A NARRATIVE STUDY OF THE LIVED EXPERIENCE OF

CONTEMPORARY AMERICAN WOMEN IN INTIMATE RELATIONSHIPS

WITH MEN WHO HAVE CHRONIC LOW BACK PAIN

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A

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Abstract

Everyone experiences pain to one degree or another, but pain that has outlived its usefulness in assisting the body to avoid injury, and causes other physical and emotional complications, is known as chronic pain. In American medicine, chronic pain is described as that which persists longer than six months and is not relieved by standard medical care. Chronic pain usually leads to a spectrum of other physical and emotional complications, including sleep disturbance, loss of appetite, and severe depression, among many others. Creating and maintaining relationships with others takes effort and energy, and this is especially true in a marital relationship. Marriage between two able-bodied people is challenging enough, so the added variable of chronic pain forms new dimensions of relationship difficulty that must be addressed.

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Acknowledgments

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Chapter 1: Review of Related Literature

"Pain is a more terrible lord of mankind [sic] than even death itself."

-- Albert Schweitzer

1.1 Statement of the Problem and Goals of the Research

The purpose of this research is to explore the lived experience of contemporary American women with male partners experiencing chronic low back pain, and to understand how these women co-construct their marital realities. I wish to understand how these women feel about themselves, their partners, and their lives together, and how they cope with unique challenges uncommon in the general population. In other words, how are their lived experiences similar to and different from mine?

My husband has suffered excruciating, debilitating low back pain for over a decade. He was a strong and respected police officer who was injured in a fall in the line of duty. Workers' Compensation immediately took over as the insurance adjuster because he was injured while working. Workers' Compensation may succeed when a person has an acute injury (lasting less than six months), but we found that a chronic condition encourages the wrath of the system, and the scorn and indifference of those who administer it.

I experienced unexpected degradation of relational communication as my husband's pain increased and progressed, and as his general health declined. As a researcher, I want to understand how chronic pain affects a couple's ability to

communicate. How do couples cope with the loss of income? How do wives of sufferers cope?

Chronic pain, the most frequent cause of disability, afflicts as many as 97 million Americans. One major problem in the field of chronic pain is defining what it actually means. The best of many definitions of Chronic Pain is characterized by the International Association for the Study of Pain (IASP) as "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Boduk, 1994, ¶ 19)

In 40% of primary care visits, pain is the chief complaint (Marcus, 2003, p. 2) Chronic pain makes up 20% of these complaints. The most common chronic pain in the United States involves the back, and it affects almost 60% of Americans during their lifetime (p. 2). As of 2000, *one fifth* of the United States population was disabled (U.S. Census Bureau, 2007), costing $100 billion annually in lost revenue, work, and medical expenses (Silver, 2004, p. 11). Remarkably, only recently has pain gained its own topic identification, despite the fact that pain is the most frequent "presenting symptom" (Jackson, 2000, p. 186).

Fortunately, the Joint Commission on Accreditation of Healthcare Organizations has developed guidelines that have increased pain treatment awareness. Until 2003, there was nothing to educate healthcare providers about caring for chronic pain patients. Physicians have traditionally been uneasy about prolonged responsibility in prescribing narcotics for their chronic pain patients. Physicians face two problems with chronic pain

care: common myths about chronic pain, and just not knowing how to address co-morbidities (Marcus, 2003, p. 2).

Chronic pain affects other people besides the sufferer, mostly their families. The cost of back pain alone includes medical care, lost wage compensation, and production loss, not to mention personal suffering (Martin, 1989, p. 6).

As a member of this massive, misfortunate demographic, my goal is to begin a quest for understanding and comprehension, rather than divorce my husband, as many women in my situation are forced to do for financial and emotional reasons.

1.2 Experience of the Sufferer from Literature

1.2.1 Historical views of pain

Pain has been a constant human condition throughout history. Evidence of suffering is documented from Babylonian clay tablets, and is reflected in the tattoos of Oetzi the iceman; the Bronze Age cadaver found in the mountains between Italy and Austria. Radiology tests on Oetzi proved that he had facet joint degeneration in the lumbar spine, so the tattoos on his low back and sciatica were consistent with where he would have been feeling pain. Oetzi's society responded to pain in a spiritual way, so a critical feature of human societies is the ability to cope with the health complaints of its citizens (Kennedy, 2003, p. 9). Pain has been a universal problem that has thus far escaped our ability to treat it. Aristotle's theory "that pain was felt in the heart" survived throughout the Middle Ages, the Renaissance, and into the mid-nineteenth century. In the 16th century, Renee Descartes proposed that noxious stimuli were conducted throughout

the nervous system to the brain and interpreted as pain (White, 2002, p. 5). Descartes' theory also held for centuries.

By the 1850's, three pain topics developed and have continued into the 21st century: *acute pain* (broken leg), *chronic pain* (migraines), and *easing severe pain without curing it* (cancer). (Meldrum, 2003, pp. 2470-71). However, Schiff's 1858 Specificity Theory declared that pain was a sensation separate from touch and other senses, and had its own sensory apparatus (White, 2002, pp. 5 – 6). Specificity Theory labeled those in chronic pain as malingerers, crazy, or addicted, and the theory became the mantra of medical schools by the 1920's. S. Weir Mitchell, a famous Civil War neurologist, was a patient-advocate for those in severe, unexplained chronic pain. He noted that burning nerve pain from a "healed" wound was the worst of all because it caused the noblest people to become irritable, hysterical cowards (Meldrum, 2003, pp. 2470-71).

With the advent of antibiotics and sulphonamides, humans have prolonged life and fought disease so that ill health itself became a disease. In understanding the trajectory of disease, we subsequently lost focus of the experience of illness. Now we must look to not only cure, but to understand quality of life and caring (Kennedy, 2003, p. 46).

Western society, based upon the pain theories of Rene Descartes (1596-1650), continues to take a reductionist, positivist approach when accounting for illness. Descartes' ideas (based upon scientific certainty) were that people could be understood when broken down into smaller, observable pieces; like a clock. Medical practice has forwarded his ideas through the centuries (Vickers, 1997, p. 11).

In 1965, Melzack and Wall theorized the "gate control" theory of pain, after there had been nothing new in pain research for 300 years. Their theory is that the brain referees the pain signals it picks up and alters the body's neuropathic gates depending on a complicated array of memories and emotions (Kennedy, 2003, p. 12).

Currently, Dr. Mark Ware of the Montreal General Hospital says we have a linear understanding of pain. There are receptors in our bodies that acknowledge painful stimuli, like heat or a needle, and those receptors send the pain message to the spinal cord. The message is picked up by another nerve and sends the message to the brain. Another nerve picks up the message and takes it to the cortex area of the brain, where we understand that we have pain (p. 7). With all these pathways and picking up and dropping off, messages get modified. The transmitters picking up and sending the messages change, as do the receptors. We do not understand these mechanisms completely, but this is the simplest way to describe it (p. 7). The traditional biomedical model of modern medicine simply does not account for the pathophysiological factors of pain, or the other factors that contribute to chronic pain and the resulting experience. The failure of the biomedical model led Melzack and Wall to propose the Gate Control Theory of pain (p. 22).

What we know today is that every person is different, that pain experiences are different even among those with the same diagnosis, and that this characterizes therapy responses. Russell Portenoy and Kathleen Foley, in their opioid analgesic studies in chronic non-cancer pain, maintain that the most successful pain control factor was intensive physician attendance, which is why pain management continues to be a burden for clinicians (Meldrum, 2003, p. 2473).

1.2.2 Biomedical and Biopsychosocial Paradigms

Contemporary pain management is born of the biomedical paradigm, which sees biology as the primary cause of disease. Pain is assumed to come directly from a biological disorder, thus objective tests locate the disease, allowing for corrective action. Psychological matters are secondary or entirely extraneous (Weisberg, 1999, p. 2).

Ironically, the more advances we create in the medical field, the more disability we create, thus increasing the need for rehabilitation and support. Those who have illness and disability are a vociferous reminder of the failure of Western medicine (Wendell, 1996, p. 96). The pain clinic Jackson speaks of in her 2000 book *Camp Pain*, threw pain patients into a pain paradox; "*pain is real, but it can only be conquered in the mind*" (p. 8). "Somehow if you are suffering needlessly, it is your fault…you *could* get better if you only *would*…you say you *cannot*, but it is really you *will* not" (p. 172)

Modern western medicine is the sole authority on describing the body to society, because it is the only one believed and accepted as truth. This is a powerful position because it has command with governments, insurance companies, employers, courts, schools, charities, and other institutional powerhouses. Western medicine asserts a promise to control nature, and many people believe in this predictability and control model. The disabled are visible, constant reminders of the failure of that promise and of science's inability to save everyone from pain, disability, and death (Wendell, 1996, p. 63, 117). Richard Zaner and Drew Leder, both phenomenologists, (as cited in Wendell, 1996) assert that since the beginning of Western medicine, the body has been viewed as a corpse instead of as a lived experience (p. 120). The third-person epistemic view of the

body has become the socially valued perspective; therefore, bodily experiences that cannot be explained are denied. A person with a body problem requires a medical description in order to gain epistemic validation (p. 122, 125).

Like a medical description, a prescription for medication resembles a souvenir, and imparts talismanic properties. Doctors are representations of medicine, and must adhere to rituals and ceremonies or face a backlash of scorn. Unceremoniously handing over medicine from a grocery bag, for example, weakens the value of medicine and makes the doctor a handler of common merchandise, never to be trusted again (Gwyn, 2002, p. 55). Medicine is an "it," has physical charm, and is easy for people to understand (p. 23). Illness is an "other" and can only be ejected with a material "it" like a medicine (p. 23). Medicine's concreteness represents biomedical success, where pharmaceuticals present a material weapon against a physical disease (p. 25).

Western medicine maintains a myth of control; we can control our looks and our health and we can have perfect bodies. Medical professionals are all quite certain of their knowledge, and rarely admit their inability to prevent or cure ailments (Wendell, 1996, p. 94).

Our Western system sees beauty and health as obvious signs of heavenly favor, while ugliness and body damage imply dirtiness, weakness, and disgrace. Pain is difficult to address because it is associated with those strongly negative qualities (Jackson, 2000, p. 182). Practitioners of the biomedical paradigm generally see death as a failure. Patients, on the other hand, measure failure in terms of suffering, lack of support, and hopelessness (Wendell, 1996, p. 137). Death is at least final, but pain can invade our

lives, torture us, and change our being (Kennedy, 2003, p. 1). One patient in Jackson's (2000) study said, "The pain has agency. It is a demon, a monster – pain is an 'it'" (p. 147).

The traditional biomedical paradigm does not address the complexity of pain, thus it is insufficient in dealing with it (Thomas, 2000, p. 683). A new medical paradigm is necessary, and the biopsychosocial model has answered the call (Weisberg, 1999, p. 2-3).

The biopsychosocial model of medical treatment addresses the biological, the psychological, and the social (Silver, 2004, p. 96). The Holmes-Rahe Social Readjustment Scale, developed in 1960, identified major stressful events that can happen in people's lives. A chronic pain couple is vulnerable to experiencing 75% of the 43 major stressors. Therefore, it is plain to see what a profound impact chronic pain can have on a marriage and a family (p. 22). The biopsychosocial paradigm does what its name implies; it takes the best of medicine and encompasses a combination of psychological, social, and cultural persuasions to identify and treat chronic pain. The term "psychosomatic" is used to refer to those people whose pain cannot be accounted for by traditional organic tests (such as migraine or hypertension). Pain doctors now understand that psychological and social issues are reflexively affected by the biological problem itself. A patient's environment can change how the brain actually processes information. In the biopsychosocial model, symptoms are regarded as a myriad of complexities converging to create and propel pain (Weisberg, 1999, p. 4).

The social aspect of illness involves those in the patient's immediate social circle, as they have influence on the patient as far as recovery and coping. Research shows that a

biopsychosocial approach is advocated in caring for those with chronic low back pain. However, this model is not currently accepted, let alone practiced, in the Western medical world (Miller & Timson, 2003, p. 40). Doctors simply feel more comfortable maintaining a doctor-patient barrier and practicing the biomedical model of searching for a lesion (p. 41).

1.2.3 Medical Labeling and Diagnosis

The medical profession sees malfunction as the antithesis of health; that people should know when they have a malfunction, and immediately seek help to rectify it. (Vickers, 1997, p. 69). *Disease* is a concept describing biological and physiological malfunction, while *illness* describes a person's awareness of the malfunction, and *sickness* refers to the appropriate social role (p. 68). Sickness represents the impact on the individual within a social group. The sick role is a set of behaviors taken on by the sick person, and accepted by others. It removes many obligations and expectations from the sufferer, who is expected to seek treatment during sickness, and includes exemptions from normal social responsibilities, the responsibility for the condition itself, and from the inability to decide to get well. The sick role is not accepted, however, until appropriate medical and social judgment is made (pp. 71-73).

The sick role sometimes depends upon its visibility to others. Many times, a chronic invisible disease like chronic low back pain does not allow a person into the sick role (p. 74). Illness becomes a social contract where one is obligated to show evidence of illness and do everything possible to overcome it. The doctor becomes a social authority

to verify the patient's ailment. Both the patient and the doctor become instruments of social control (Gwyn, 2002, p. 62).

In order to get proper health care from a medical professional, one must focus on one's disability, which is often a source of shame, or seen as a "defect of the self." Those with invisible disabilities have the added challenge of having to explain why they need service, and that itself can be a shame-inducing event (Matthews & Harrington, 2000, p. 412).

The endless subjection to examinations, tests, surgeries, and medicines leaves patients angry, frustrated, bewildered, and discouraged with medical science and doctors. Doctors themselves become angry and frustrated when nothing works. People are conditioned to believe that modern medicine can cure and repair everything; so many families and patients blame doctors, even when nothing more could be done, or when something goes wrong. (Wendell, 1996, p. 129). The ensuing professional advice is "learn to live with it." No matter what a person's social status is, and how trustworthy they are, developing an unknown ailment automatically brings their sanity into question. The patient is seen as pretending, malingering, resisting treatment, or becoming mentally ill, and the "it's in your head" diagnosis is not uncommon. Patients might know better, but friends and family believe the doctor, as do insurance companies, courts, and other social service agencies. Thus, one unexplained ailment can devastate a person's cognitive and social authority (Wendell, 1996, p.126).

The label of disability is a double-edged sword. Those with the label are stigmatized, but without the official label (social recognition), they are not entitled to

help from family, doctors, government, insurance companies, or charity. (Wendell, 1996, p.129). Some patients cry with joy when receiving a devastating label because it validates their experience and restores them to society (Strong, 1999; Vickers, 1997; Wendell, 1996). Providing patients with diagnoses is an essential "first step in initiating cognitive restructuring." Those in Gullacksen and Lidbeck's 2004 study who received diagnoses were greatly relieved and felt "the beginning of a whole new process and a long period of healing" (p. 151).

Society expects patients, already devastated with unexplained illness and total lack of support, to negotiate equally with socially powerful doctors and insurance companies (Wendell, 1996, p. 131). It is in the insurance companies' best interest to recognize as few medical labels as possible while still advertising their value to consumers. Likewise, it is in social programs' best interest to recognize as few medical labels and conditions as possible without drawing the attention of political opposition (p. 132).

1.2.4 Medical and Lay Discourse

In the social construction of the body, there are two discourses: that of the body and that of medicine. Because our current view of the body is completely medicalized, it is difficult to separate the two. In 1973, the philosopher Michel Foucault coined the term "medical gaze" to describe the scrutiny to which our bodies are constantly subjected (Gwyn, 2002, p. 8).

A 1991 ethnographic study by W. S. Rogers asserted that Western medicine has sold itself as the sole provider of cures by discrediting other methods and practitioners as

"quacks" (Gwyn, 2002, p. 45). Additionally, Gwyn (2002) states that biomedical reality is maintained through "legitimation," which is Berger and Luckmann's concept from 1967. Legitimation has four levels: 1) medical language that upholds a vision of how the world really is, 2) lay language that upholds proverbs and clichés, 3) theories explaining medical knowledge (i.e. germs) which can always be trumped with new scientific discoveries, and 4) internalization of symbols of medical knowledge where worldviews are perpetuated by expert legitimation (p. 45).

1.2.5 Metaphor and Narrative

Because human reality is located in language, health and illness are expressed through language, and metaphor lets us storify our lives (Gwyn, 2002, p. 47). All knowledge is contained in the past, so discourses of illness and medicine are crucial and mutual because the patient learns more about his or her experience by telling a story to the doctor (p. 168). We are in a metaphorical war against disease, which thrashes about against the sophisticated armor of the medical establishment, and our ultimate goal is to win the war. Modern medicine has created professional control, making society dependent on it, and ignoring the politics involved with creating such dependence. It has taken health control away from the individual and placed it in the institutionalized medical machine. Crusades aimed at persuading people to change their unhealthy behaviors are seen as virtuous endeavors (Gwyn, 2002; Vickers, 1997).

Foucault believed that the body is ground central for political and philosophical control, and he posited that the body is governed by institutions and also by discourse (Gwyn, 2002, pp. 10-11). Bodies are of central importance in the disciplines of politics,

psychology, sociology, literature, theology, communication, and so on. When our bodies are a theater of struggle, they become the focal point of our definition of self and others (Do & Geist, 2000, p. 51). In 1980, Lakoff and Johnson stated that metaphors provide the foundation of the conditions for our constructed reality (Gwyn, 2002, p. 24). Nature is used as a metaphor in illness. For example, nausea is described as a "wave," while pain is a "vise." Patients communicate ailments to doctors with metaphor in order to gain recognition and label, and to get the charm of a prescription (p. 31).

Barbara Duden's 1991 look at an 18th century doctor's notes found interesting articulation and specificity of suffering. Female patients described their symptoms in ways like "womb anxiety," "choking in the breast," and "throbbing of the heart." Eighteenth century patients conceived of and explained their sufferings differently, and even perhaps experienced their bodies differently, than we who live under the authority of Western medicine (Wendell, 1996, p.137).

Acronyms of disease, like HIV, MS, and ME are now legal tender, mirroring the medicalization of our language. Everything in our environment seems to induce cancer or be otherwise unhealthy. Health is now seen as the natural state of being, even though it is not. The World Health Organization defines health as overall mental, physical, and social well being, which is actually only a dream for most people (Gwyn, 2002, p. 7).

Narrative is the purposeful reconstruction of past events across time, and is critical within both lay and medical discourses. Narrative helps us arrange events in order to make sense of them, and to give meaning to our experiences. Famed neurologist Oliver Sacks says that each of us is a narrative, continuously constructed through our

perceptions, feelings, thoughts, actions, and our spoken narrations. As cited in Gywn (2002), Kierkegaard (1987) suggested that we live our lives facing forward, but account for them by looking back (p. 141).

1.2.6 Micro and Macro Conversations

Elaine Scarry's 1985 opinion (as cited in Strong, 1999) is that pain is language shattering. Those in pain seek relief, understanding, and care from those closest to them through language. When efforts stall, people experience impotence, frustration, and continued suffering. There are two principal types of conversation: macro and micro. In macro-conversations, we make use of cultural customs of understanding and talking about pain, where we try to communicate the pain experience to others (p. 1).

Micro-conversations serve to mold the experience of pain and suffering. These conversations make pain comprehensible to the speaker and others, and they are the vehicles we use to negotiate our comfort needs. Tom Strong (1999) presents a social constructionist theory suggesting that pain is negotiated through conversations. Pain meanings must be negotiated or there is no chance to minimize suffering. Talking about pain includes recognizing and describing it in addition to requesting assistance from those we are closest to (p. 1).

Macro-conversations use cultural customs to understand and talk about pain, and communicate the pain experience to others. Macro-conversations force pain into the personal realm to discourage outward signs of suffering through the use of words like "malingering," "hypochondriac," and "wallowing." A sufferer must maintain a "stiff upper lip" in order to maintain normal social relations, no matter how difficult it is. There

is social virtue in keeping pain to oneself, but stifling it only compounds the pain experience, which is already hard to hide (Strong, 1999, p. 3). When articulation of pain fails, society and medicine label sufferers as neurotic, or worse. Patient blaming is evident in litigation, workers' compensation benefits, and medication use (p. 3). These macro-conversations (cultural discourses) are a mirror of the experiences our culture or society shares, and each type of social community offers different macro-conversations. For example, football players discuss pain differently than cancer patients. The ways in which we talk about our physical sensations, suffering, and emotions lays the groundwork for our experiences of these phenomena (p. 3).

1.2.7 Meaning of Chronic Pain

Acute pain is good in that it serves to warn us of current or future tissue damage. Chronic pain is bad because it doesn't go away, nothing can make it go away, and it compels us to question its meaning. Tissue being repaired should not be used, so our body tells us the site is sore, and to stay off of it. Some tissue injuries never heal, like arthritis. Chronic pain comes from the activated nervous system associated with healing, even though healing will never happen (Kennedy, 2003, p. 3).

The standard of stimulus-response is what doctors and physiologists have concentrated on for centuries. Melzack (as cited in Kennedy, 2003) proposed adding the brain into the equation: adding the warehouse of stored memories, dreams of the future, and learned and inherited responses to pain (p. 14). Melzack and Wall's Gate Control Theory has replaced Descartes' one-way theory. Descartes proposed that, for example, a hammer hits a thumb; thumb sends message to brain; alarm sounds. But that doesn't

explain why a carpenter might not notice a thumb hit while a baker would. Descartes one-way theory also does not explain phantom limb pain (p. 14).

Melzack developed the McGill Pain Questionnaire. He began by collecting a list of words people used to describe their pain; words like "searing," "sharp," "burning," and "devastating" (p. 17). He then grouped words into categories, and found that the more intense a person's pain, the more words he or she used to describe it. "Hot" describing words are not as severe as "scalding," and the clusters of words people use to describe their pain can be interpreted so that one can distinguish between different types of back pain, face pain, and so on. The questionnaire is now used all over the world (p. 19).

1.2.8 Physical Consequences of Chronic Pain

The human spine consists of two anterior curves and one posterior curve. The body's muscles keep these curves in place, and the curves assist us in carrying our physical load by walking, running, bending, and twisting (Escogue & Gittines, 1998; Miller & Timson, 2003). Any alteration in the spine, or damage to the muscles, will change the location of the lumbar, thoracic, and cervical curves, throwing the entire body-balancing act into chaos. Muscles fail at varying times and rates depending upon a person's lifestyle. Eventually, the muscles give in, and the spinal S curve weakens, as does the body's ability to bear the load, strength, and absorb shock. The spine is at the mercy of gravity. If there is no flexing or flexibility, there is only greater rigidity. As a last resort, says Escogue and Gittines (1998), the body contracts muscles, "...and since the upper torso is designed to flex forward, the muscles grudgingly allow flexion, until the structure of the spine reaches its limits and freezes in place" (p.117).

Celeste Johnston (as cited in Kennedy, 2003) is a professor at McGill University's School of Nursing, and says we know that when presented with pain, the brain releases endorphins, which descend to block pain messages. Pain is not merely a symptom; it is something to be dealt with on its own (p. 34).

The pain of a back spasm essentially blocks a person's rational decision-making abilities, and makes them unable to work or think clearly during the pain (Escogue & Gittines, 1998; Miller, 2003). Studies have shown that chronic pain patients have trouble with running, dancing, walking, sitting, using stairs, sleeping, sex, lack of energy, concentration, depression, and have suicidal thoughts. Depression is quite common in chronic pain patients (White, 2002; Jackson, 2000). Many patients reported frequent irritability, anxiety, tension, and anxiousness. Many found that socializing was so frustrating that they gave it up (Jackson, 2000, p. 46). One sufferer, a research scientist, said she could not do addition or think through sentences during a pain attack. One man said he often thought of suicide, but figured his 8-year-old daughter would rather have a nasty, cranky father than no father at all (p. 44).

Chronic low back pain can be progressive, constant, and/or erratic, and it affects the physical and psychosocial roles of family, friends, and work (Lyons & Meade, 1995, p. 183). Communication is critical to healthy couples' functioning. Rolland (1994) states that Gottman (1994) discovered that particular patterns of interaction led directly to dissatisfaction and divorce, including criticism, defensiveness, contempt, and withdrawal. In early life-cycle illness, both partners can have an enormous sense of future loss and life robbing (p. 378). Young married couples can have trouble finding other young

couples in similar situations, so they become more isolated. Support groups are normally disease-specific, and few focus on couples (p. 378). Healthy couples avoid chronic illness couples due to discomfort and fears of vulnerability, while chronic illness couples avoid others, becoming self-conscious, and furthering their own insecurity and isolation. They are coping with issues normally found in older life-cycle relationships, so they are often out of sync with their own age group (p. 378).

Romano, Turner, and Jensen (1997) found that having a depressed family member tends to result in less cohesion and increasingly more conflict. Depression is amplified because there are fewer positive experiences to cushion the effects of conflict within the relationship (p. 392). A national chronic pain organization survey found that 50% of members had seriously considered suicide. This alarmed the authors because most organization members were well educated and financially secure, and had been actively involved in finding ways to cope with their pain (Thomas, 2000, p. 685). Strandmark (2004) concluded that when disease is taboo in society, an afflicted person feels shame, guilt, and self-blame. Shame is the unwelcome exposure of vulnerabilities, and makes people aware and afraid of what others think of them. When one's autonomy is threatened, and loss of freedom becomes a burden, suicide becomes a solution (p. 142).

1.2.9 Narcotics

Chronic pain is not simple to fix, and medication does not get rid of the pain. Only about half of chronic pain patients who receive comprehensive multidisciplinary treatment can actually return to work. One myth is that if chronic pain improves, then the other problems (depression and disability) will magically disappear. Untreated or under-

treated psychological issues can actively hinder a patient's motivation to follow through with recommended treatments (Marcus, 2003, p. 3).

Worries about addiction to pain medication have resulted in underutilization of narcotics and opioids in non-cancer pain treatment, so many sufferers are not being given the drugs they need to alleviate their pain (White, 2002, p. 1). Family perceptions have an influence on medication, and their misconceptions of addiction can cause the patient to be under-medicated (Silver, 2004, p. 13). Because many prescription drugs sometimes contribute to problems of tolerance, physical dependence, addiction, and abuse, the US Drug Enforcement Agency labels them "controlled substances." These controlled substances have street value, so doctors must use a special USDEA number and a special USDEA form to prescribe them.

Tolerance is when a patient requires increased doses of medication to get the same level of pain relief, because the drugs become less effective over time. The doctor has to scrutinize patients who need increased doses. ***Physical dependence*** is when withdrawal symptoms occur when medication is stopped. If the medicine is gradually reduced, there is no problem. Tolerance and depression are physical problems, *not* a sign of addiction or abuse (p. 108). ***Addiction (psychological dependence)***, in general, is a compulsive use and craving of a substance for mood-altering purposes. Addiction is when a person cannot control their use of a drug, compulsively uses and craves a drug, and continues to use it despite obvious current and future harm in doing so (p. 109). Addiction in chronic pain patients is very rare, less than 0.00034 % (Meinhart & McCaffery, 1983, p. 332), because narcotics *diminish pain* instead of making the user

high. ***Abuse*** is defined as the use of a substance contrary to approved medical use or social patterns, and involves "doctor shopping," or going to different doctors to obtain controlled substances (Silver, 2004, p. 111). Despite the blaring differences between addicts and chronic pain patients, studies of addicts have helped improve our understanding of how opioids react in the human body (Strong, 1999, p. 3).

1.2.10 Identity/self-esteem, Emotions, Depression

Definitions of disability influence self-identity in the disabled. Not only does the label carry stigma in most societies, it also forces the so-labeled to deal with unsavory viewpoints and expectations projected onto him/her as a member of a stigmatized group (Wendell, 1996, p. 12).

Accepting disability can involve a profound identity change, especially for those who strongly identify with their able-bodied occupation that they can no longer perform (Wendell, 1996, p. 26). Charmaz's 1983 study (as cited in White, 2002) asserts that identity is lost when activity is reduced, and self-concept is slowly destroyed in social isolation. Chronically ill people have to give up activities or work they enjoyed, and try to find meaningful things to do with their time within their restricted physical limits. Identity is reevaluated through reviewing past lives and thinking of possible futures (p. 20).

When a back injury happens on the job, a new set of rules applies. Litigation is a very upsetting, lengthy, and stressful process. Families are often put under surveillance and secretly videotaped. Constant financial deprivation and lowered standard of living can have a severely detrimental affect on a family's well being (Silver, 2004, p. 55).

White (2002) found that Workers' Compensation issues "...included rejected legitimate claims, cessation of payment for treatments that were helpful, and age limitations on job retraining" (p. 59). The workers' compensation system assumes that injuries heal, and does not help those who have long-term disability (p. 59). Men in White's 2002 study seemed to have more problems coping with job loss than women did. Men calculated their quality of life lower than women, most likely because inability to work negatively contributed to their self-concept more so than women (p. 60). Men tend to judge their self-worth according to their employment, whereas women tend to judge their self-worth according to their roles as mothers, grandmothers, and wives (p. 62).

Psychological mourning of the loss of ability is a natural reaction manifesting in depression and emotional withdrawal (McDaniel, 1976, p. 9). Marra and Novis's 1959 study (as cited in McDaniel, 1976) observed 52 disabled husbands and fathers. The men said the primary changes in their family relationships were, in order of importance, 1) wives had to take on more home management responsibility, 2) social and recreational events were reduced, 3) children assumed more duties, 4) financial debt, 5) no additional children, 6) wives needed gainful employment, 7) more marital discord, 8) changed plans for children's education, and 9) changed living accommodations. From the men's perspectives, family relationships suffered considerable turmoil because of disability (p. 49).

People with illness like chronic low back pain often speak about their lives before injury as if they were a different person. Chronic illness sufferers play host to several psychological responses; including depression, hostility, self-doubt, self-loathing,

suspicion, regression, uncertainty, interpersonal insecurity, guilt, and loss of self-esteem, to name a few. The degree to which these anguished responses are felt relate directly to the social acceptability of the illness, how clear the diagnosis is, and how potentially severe the illness is. These three things also determine how much care, trust, and respect a chronically ill person receives (Vickers, 1997, p. 66).

1.2.11 Assumptions

Misunderstandings leading to bad feelings occur when extended family members do not realize the depth of the problem. A cycle of wanting to help, but not being able, can foster negative behaviors in extended family members. It is easier for them to avoid the person in pain than to try to continue a relationship. Often, family members yearn for the person they used to know, instead of the person they now know. The pain-induced personality changes can make communication difficult, and it can take years for family to adjust to the new situation (Silver, 2004, pp. 87-88). Gullacksen and Lidbeck (2004) report that most patients try very hard to conceal their pain in order to avoid negative perceptions from others because "...suffering in silence [is] socially necessary" (p. 152).

Chronic pain, invisible to others, garners hostile glances and doubts (Thomas, 2000, p. 691). When speaking to a doctor, some patients feel more at ease disclosing their problems, leading the doctor to believe patients "exhibit exaggerated pain behavior" (Gullacksen & Lidbeck, 2004, p. 150).

Rejecting a suggestion from a relative or friend means that one does not want to be "fixed." Conversely, trying every remedy is a full time job that will exhaust personal finances (Wendell, 1996, p. 98). If sufferers do not create meaningful lives, then they are

not adjusting. If they do create meaningful lives, then they are motivated to remain ill. Speculation on the part of friends, family, and doctors can increase the self-disgust, blame, and guilt struggling ill people already feel. There is a general notion that frame of mind is all one needs to overcome anything. If one does not get well, one has the wrong attitude (p. 102).

1.2.12 Language

Illness is created, maintained, and transformed through language. We understand our illness through the dialogue of doctors, nurses, our social circle, our family members, and we repeat the words we hear from all of them (Gwyn, 2002, p. 6). We are each involved, through language, in the completion of other human beings, and we are responsible for sustaining our social worlds. Conversation shapes how pain is experienced, and conversation is how we construct and reconstruct our own and each other's shared experiences (Strong, 1999, p. 5). Jackson (2000) posits, "...one cannot, and perhaps should not, attempt to contain, categorize, or measure pain with words" (p. 193).

Pain is a language itself that fights with everyday language (Jackson, 2000; Wendell, 1996). Language is inaccurate, and it favors the medical establishment. Clinicians have their own powerful answers and solutions that often do not agree with those of the patients (Vickers, 1997, p. 61). Clinical discourses in chronic pain are rife with gaps, inaccuracies, over-generalizations, and institutional self-protection, which ultimately prevent anyone from understanding the challenges pain sufferers face (Jackson, 2000, p 14).

Scholarly literature shows that even specialized pain clinicians have ambiguous understandings of chronic vs. acute and real vs. imagined. All of these misunderstandings are rooted in our spoken language. Even specialized clinical language fails. For example, there is a distinction between the lay word "pain," and the clinical word "nociception" (Jackson, 2000, p. 157).

Social construction theory argues that our actions and assessments communicate our understood meanings through dialogue. These conversations are sprinkled with information from the media, cultural and gender ideas, and from the conversations we have with ourselves internally. John Shotter (1995), (as cited in Strong, 1999), says that our words are like prostheses for negotiating our world's physicality. The meanings of our words help shape our experiences, and differences in these meanings must be negotiated within our relationships (p. 2).

1.2.13 Impoverishing the Disabled

Capitalism is critical to the Western notion of success, because it thrives on fully functioning individuals to supply value to organizations. Illness and disability immediately contradict the functioning aspects of our social system, because they prevent individuals from performing at optimal levels. Health is a capitalist society resource, and sick people do not fit nicely into capitalist structure (Vickers, 1997, pp. 36-37).

Our society promotes socially constructed capitalist, individualist, and functionalist expectations, and creates negative attitudes towards illness and disability. Those attitudes include encircling illness and disability in constructs of deviance, labeling, stigma, and discrimination (p. 35).

White Anglo-Saxon Protestants are considered the dominant ethnic group in America. They believe in hard work and personal achievement, with the male providing money for the family, and the female rearing the family. "Good" behavior includes self-reliance, hard work, and planning for the future (Meinhart & McCaffery, 1983, p. 128). In the U.S., impairment is viewed as the worst thing that can happen to a person, and such cultural stigma can completely seize the sufferer's identity. As a result, people who are suffering attempt to conceal their "deviance" in order to avoid mistreatment (Vickers, 1997, p. 75).

Susman (1994), as cited in Vickers (1997), defines stigma as those traits (of groups or individuals) that evoke negative responses from others. It may be argued that disability doesn't hinder individuals as much as the social responses to their disability. Historically, stigma was a visible mark of shame, and the results were discrimination and ostracism, thus defining ill persons as much or more than itself. Stigma thus becomes not only an observable trait, but also a reflection of moral inferiority and depravity (p. 46).

Because of the Americans with Disabilities Act, employers now fear litigation, and discrimination against the disabled has actually increased (p.19). Many believe that disabled workers are malingerers; that they choose to stop work and adopt a sick role in order gain benefits (p. 85). Many pain patients see the medical community as bequeathing value-laden labels onto them, insinuating that pain is simply an excuse from work and social duties. This institutionalized perspective unfortunately develops into a larger societal viewpoint, and subsequently, the public at large behaves similarly toward chronic low back pain patients (Miller & Timson, 2003, p. 39).

Wendell (1996) suggests that many people who do not experience chronic pain often believe that if a sufferer simply searches for the psychological or spiritual meaning behind the pain, it will go away (p. 174). Employer leave programs and insurance companies operate on the dichotomy of either "fully disabled" or "fully able," which relegates chronic conditions to hopeless conditions (p. 20)

Insurance companies, protecting their profits, define disability as narrowly as possible without risking lawsuits (p. 24). Bureaucrats administering "benefits" to the disabled often believe they are handing out more than is "deserved" (pp. 42-49). Social assistance benefits are less than what can be earned in the work force to create an incentive for people to seek and keep employment. When the disabled have limited access to assistance of any kind (rehabilitation, medical care, communication services, protection from criminals), such limitations serve to propel them further into isolation, poverty, and despair. This failure to create ability within marginalized groups makes disability socially constructed. Poverty is the most disabling circumstance for those who need the most help because they can barely afford the basic necessities of life, such as medicine, personal care, personal aids, and clothing, let alone money to retrain for a job (p. 41).

Lawmakers and other non-disabled social power brokers are so concerned with the few people who will "socially hijack" disability resources that the truly needy are not really ever considered. Unfortunately, many lawmakers fail to recognize that real assistance to the disabled could significantly cut costs overall (p. 51). Our culture constructs the reality that disability is a personal problem, not a social one. Disabled

people are expected, with their own astonishing efforts, to simply overcome any obstacles they encounter in everyday life. The public adores and applauds the disabled who do so against enormous odds, therefore every disabled person must meet that ideal (p. 52). The media reinforce the idea of disabled people in the outstanding/helpless dichotomy. The disabled are either heroic by "overcoming" their disability, or they are helpless, angry, and worthy of charity. They are rarely portrayed as the average everyday people they are, leading the same complex lifestyles as everyone else (Nemeth, 2000, p. 40). This perspective increases the "Otherness" of those with disabilities because many disabled cannot "overcome" their physical condition (Wendell, 1996, p. 64).

1.2.14 Lived Experience

LeShan (1964) (as cited in Bral, et al., 2002) likened the lived experience of people in chronic pain as that of an ongoing nightmare (pp. 1-2). Horrible things are done to the sufferer and more is promised; other people and institutions are in control, and there is no limit to the suffering or end in sight other than death. Chronic pain treatment is usually limited to the site of the pain, ignoring the side effects of drugs or subsequent musculoskeletal ailments, and certainly the resulting psychological effects. A 2001 study by Comley and DeMeyer found a 90% satisfaction rating by pain patients at Baylor University Medical Center, a pain clinic following the guidelines set forth by the American Pain Society. Most people, however, do not have such fortune, and often do not even get an adequate diagnosis, so pain treatment nationwide is generally poor (pp. 1-2).

A chronic illness, like low back pain, drastically reduces financial, physical, work, and social resources. The consequences are diminished intimacy, companionship, activity, and communication, which result in a complex mixture of lost income, role changes, and marital stress (Braithewaite & Harter, 2000; Lyons & Meade, 1995). It can be progressive, constant, and/or erratic, and it affects the physical and psychosocial roles of family, friends, and work. Our longer life spans come with disabilities and other health problems (Lyons & Meade, 1995, p. 183). Chronic pain is not just an individual experience; it dramatically affects family functioning, and creates turbulence (Silver, 2004; Lemmens, et al., 2003).

With chronic pain patients, energy is money, and one has to consider how to spend it (Silver, 2004, p. 93). The person in pain spends a significant amount of time and energy seeking medical attention. Side effects of medicine alone cause a myriad of other problems, including lowered energy (p. 24). Angela Mailis Gagnon, Director of the Comprehensive Pain Program at Toronto Western Hospital (as cited in Kennedy, 2003), says people in chronic pain usually go through several doctors before finding some relief, and managing chronic pain is only a small part of the entire experience. A person can distract him or herself with music, a hobby, or something that helps diminish the intensity of the pain, but when a person is feeling vulnerable, he or she tends to focus on the pain. The pain is then amplified and has an even greater effect on life (p. 7).

Intense feelings of anger, death wishes, and escape are normal and natural, and sometimes discussion about these emotions can counteract shame and guilt; however, frustrating moments between pain couples can be horribly cruel. For example, one

woman wished her husband could experience her pain for five minutes, and her husband responded that he wished she would die so he could get on with his life. When couples can accept and endure these "cruel" emotions and forgive themselves and each other, they become stronger and remain functional (Rolland, 1994, p. 330).

Ill men face problems of dependency and failing to rise to the social role of dominant male and self-reliant family provider (p. 336). The medical establishment, by focusing on the ill partner, promotes the idea that the definition of the illness belongs to the ill partner. Both partners need to question that assumption, not allowing the illness to belong to just one half of the partnership. When the illness *belongs* to only the ill partner, then all communication becomes skewed, and issues of power and control become dysfunctional, resulting in resentment, guilt, and intimacy erosion. The ill spouse can control the well spouse in the "sick role," or the well spouse can enforce power with gender-related role expectations (p. 330)

1.3 Experience of Mate from Literature

1.3.1 Spouse and Family

When a spouse takes over household duties, the added responsibilities do not reduce the undesirable effects of chronic pain, and, in fact, it can increase stress when the spouse spends more time out earning money to cover medical bills and other expenses, leaving the patient alone and withdrawn from social contact. Some spouses are unable to interpret the situation to effectively buffer themselves against stress (Silver, 1994; Snelling, 1994), as chronic pain changes the dynamics of the spousal relationship, and the well spouse experiences vastly increased chores. For those who have children, the well

spouse is in charge of getting the children ready, household chores, chauffeuring, and all of these tasks can be overwhelming (Silver, 2004, p. 24). Cook (1998) reveals that:

> Ironically, it is the family members who often silently suffer the brunt of the chronic pain patient's problems. It is the family who listens to the complaints and pleas for help. It is the family who frequently can be found calling the physician or running to the drug store at inconvenient times. It is also the family members who are deprived of a normal life. Living with a chronic pain sufferer can place stress on the family's entire lifestyle such that emotional reactions become commonplace and relationships are strained to the breaking point (p. 550)

Wedding vows are said during times of good health, when "in sickness" doesn't seem likely. As we get older, we realize that we will have to face the "sickness" at some point. Newlyweds go into marriage expecting defined roles, or agreement about how daily life will be handled. When one person is hit with chronic pain, roles become reversed or changed without consent, and often, without recognition (Silver, 2004, p. 21).

Chronic pain intensity waxes and wanes causing good days and bad days. On good days, some people over-exert themselves, and subsequently increase their pain for several days. This can cause fear of causing more pain with activity when the pain eventually wanes (p. 12). To heal, it's important for pain spouses to recognize the behaviors that cause their well spouses stress (groaning, grunting), or relying too much on the well spouse for assistance. Pain spouses also are usually depressed and angry, feeling unattractive and unlovable, which is not necessarily how the well spouse sees them (p. 32). Well spouses must understand that the pain spouse is feeling insecure,

stressed, and frustrated, to name a few. By encouraging the pain spouse to do as much as they can, self-esteem can be improved, as opposed to doing everything for them and the patient feeling helpless (p. 33).

Family plays a critical role in chronic pain, as they are the first resource of care for sick and disabled members. A majority (70-90%) of health problems are dealt with outside the medical gaze. How a disabled person describes his or her symptoms is socially constructed within the family. Until 1994, the role of the family in chronic pain was never sufficiently considered. First, physiological causes are sought, and when that turns up nothing, then family constructions can either lessen or increase the pain problem (Snelling, 1994, p. 543). A negative cycle of positive reinforcement to pain behaviors can ensue, gaining the sufferer more support and avoidance of activity. This lack of activity leads to muscle atrophy and more inactivity. Snelling suggests looking at the degree of distress expressed by family members dealing with chronic pain patients, as pain manifests in all aspects of life and has a considerable impact on the patient's family (p. 544). Roles become unbalanced, and the sufferer's constant presence in the house can interfere with chores. Arguments result from the pain, and spouses often put the sufferer's needs above their jobs, which can cause career and wage stagnation. Child behavior tolerance is diminished, and contact with the children is strained due to moodiness. Children sometimes mimic a parent's pain in order to seek attention, causing conflict between parents. Children often develop anxiety worrying about their chronic pain parent (p. 548)

Snelling hypothesizes that when effective coping mechanisms are in place, there is less negative impact on social relationships (p. 549). Further research is necessary to determine how a couple remains stable when faced with chronic illness, and the ensuing emotional processes at play within the relationship (Boyd, 2001, p. 71).

Smith (1999) used a systemic organizational framework to understand the family functioning of chronic pain patients. Most theories regard the family as a unit constantly seeking stability or homeostasis. Systemic organization sees the family unit as an evolutionary system that is constantly engaged in interaction with surrounding systems. A family unit is an open system that adapts to change and attempts to maintain harmony and free energy flow both inside and out. Incongruence manifests itself in tension and anxiety (p. 544). Because families have the responsibility of caring for a member in pain, they define and maintain the health of all members. Chronic pain is seen from three angles: a symptom resulting from family dynamics; an agent shaping family dynamics, and a force maintaining family practices. Because chronic pain affects more than the sufferer, a systemic organization perspective of family should be involved in the chronic pain treatment process (Lemmens, et al., 2003, p 21).

The connection between pain and failure is a masculine trait. "Real men" don't show or talk about pain because not speaking is a sign of righteousness. As citizens, our culture expects us to independently seek solutions and remain hopeful, but pain centers and doctors often tell sufferers to live with the pain, creating an impression of giving up and indicating that attitude among clinicians. In fact, a sufferer who continues to hope for a diagnosis, cure, or other relief is often labeled in medical records as "resisting

treatment," or being difficult (Jackson, 2000, p. 182). One patient said his chronic pain clinic encouraged him to both accept his pain, and to change it (p. 184).

1.3.2 Well Spouse/Caregiver

Marital problems are common in chronic pain couples, with spouses reporting increased distress, depression, and illness (Martin, 1989; Silver, 2004; White, 2002). Research shows that caregivers experience higher levels of distress, depression, anxiety, and physical health issues than their non-caregiving counterparts. Caregivers of chronic pain sufferers are particularly distressed because chronic pain is uncontrollable, and caregiving is unrewarding. Caregivers receive little help or social reinforcement, and often must neglect their own needs, leisure pursuits, and hobbies, in order to support the loved one (Kurylo, et al., 2001, p. 2). Spouses of chronic pain patients often report frequent neck and shoulder pain. Chronic low back pain appears to affect both spouses in terms of psychological distress (Saarijarvi, et al., 1990, p. 121).

Mehta & Ezer (2003) assert that sufferers often do not realize the amount of stress their pain causes their spouses, and that spouses suffer great distress when their loved one is in pain. Mehta & Ezer's respondents reported that pain robbed them of living a normal, healthy life (pp.2-5).

A new caregiver experiences many emotions, including: worrying about medical care, money, transportation, and home modifications; worrying about time off work, work schedule changes, job changes, or work cessation; and stress about monitoring health (Kurylo, et al., 2001, p. 2). Patient-caregiver roles can skew a relationship because power and dominance roles are affected. Sustaining intimacy depends upon creating

caregiving boundaries. Patient-caregiver roles compete with equal partner roles, and must be openly discussed. A disabled husband will no longer be able to perform physical tasks or provide the same income, but he can still communicate and give emotionally (Rolland, 1994, p. 332).

The pain-full spouse often cannot socialize or travel, and the well spouse limits recreational activities to accommodate the increased workload at home. This leads to isolation and loss of emotional support from friends and family (Silver, 2004, p. 29). Chronic pain isolates people by resetting their personal parameters, thus physically and emotionally creating distance between them and others. Honest and authentic relationships are difficult to come by, or do not exist at all. The most critical relationships are those that patients have with their physicians. Even when doctors are impersonal, rude, and cruel, patients continue to hold out hope for a doctor who can help them. They are willing to subject their bodies to numerous, lengthy, invasive, expensive tests and surgeries time after time (Thomas, 2000, p. 692).

Pain is expressed in grunts, groans, cries, winces, screams, and so on. We do whatever we can to help a loved one in pain, but sometimes there is nothing we can do. In scholarly literature, pain expressions are often called pain behaviors, which is what people do or say to let others know they hurt (Silver, 2004, p. 4). A spouse may respond to the groans, screams, and wincing behaviors with help, or with resentment, both of which can harm the relationship. Silver (2004) states that these pre-language behaviors are considered "maladaptive," and that effective communication happens not through groaning and grunting, but through honest and loving communication (p. 5). Contrary to

that statement, Gullacksen and Lidbeck (2004) say "pain behavior" is rarely maladaptive or reversible, even though the medical establishment commonly believes so (p. 150).

1.3.3 Couple

Any kind of chronic pain or disorder can wreak havoc in a couple's relationship. Couples must maintain the balance of a mutual relationship while taking on the roles of patient and caregiver. Planning ahead and a normal lifestyle become impossible. Chronic illness has profound consequences for a couple's relationship and the sacred boundaries within (Rolland, 1994, p. 327); and research comparing marital satisfaction before chronic pain to after is sparse (Boyd, 2001, p. 69). For couples with an illness, boundaries must be clarified because these couples tend to spend a lot of time together compared to "normal" couples. This forced association challenges couple's previous separate/togetherness balance. When a chronic illness occurs, couples become fused and connected, and naturally occurring relationship processes are interrupted by chronic pain through lack of social support, more isolation, more loneliness, and more anger (p. 13).

Some common emotions that these couples cope with are the five stages of grief defined by Elisabeth Kubler-Ross (as cited in Silver, 2004). The stages, experienced at different times and intensities, are: denial, anger, bargaining, depression, and acceptance. A substantial amount (25 - 60 %) of mostly well spouses admit marital dissatisfaction (Romano, et al., 1997; Silver, 2004); however, data from Canada and the United States indicate that divorce rates are higher among the disabled than the able bodied (Braithwaite & Harter, 2000, p. 19).

Most research focusing on the interpersonal relationship between pain patients and their spouses employed an *operant theoretical model*, suggesting that the spouse reinforces and perpetuates patient pain behavior and disability (Romano, et al., 1997; White, 2002). Over the years, researchers have realized that couple and family functioning are multidimensional constructs, where cohesion, flexibility, and expression interact with behaviors, disability, and distress in ways we do not yet fully understand. A new perspective now confronts the operant theoretical model. Emotional support is critical for adjustment. Patients in Gullacksen and Lidbeck's (2004) study did not tend to seek support for secondary gain, and in fact dependence became a problem for them. The authors found no support for the operant theoretical model, which indicates that supportive spouses encourage sick-role behavior. Dependence actually provoked feelings of guilt and low self-esteem (p. 151).

Mehta & Ezer (2003) refers to Kristjanson and Ashcroft's findings that at least the medical establishment now sees *cancer pain* as a family phenomenon, not just an individual one (p. 1). Jamison and Virts (1990) (as cited in Boyd, 2001) found that those chronic pain sufferers with a supportive family felt less pain intensity, less dependence on medication, and more activity (p. 63). A supportive spouse helps create much higher levels of martial satisfaction than those spouses who withdraw (Boyd, 2001; Gullacksen & Lidbeck; 2004; Romano, et al., 1997).

Partners experience social isolation in tandem with their suffering partners because friends do not appreciate listening to frustrations and problems (Miller & Timson, 2003, p. 40). Partners develop an assortment of coping strategies in order to

function within the relationship, including expressing love, dealing with the problem, having hope that things will improve, and constantly searching for information that will assist them (p. 40). Men in chronic pain experience depression as a result of physical loss, job loss, social isolation, physical limitations, hopelessness, and frustration. Health professionals who cannot lessen the pain reinforce these feelings (Kerns & Turk, 1984, p. 849), and doctor appointments become little more than pill dispensing visits (Miller & Timson, 2003, p. 39).

Kerns & Turk (1984) hypothesized that as support decreases with increased pain over time, marital support perception increases. Having a supportive wife is so important for a Western-socialized man that not having one is almost a guarantee of depression (p. 850). A major risk is that the illness will dominate the relationship itself, and most couples grieve for the relationship before the illness. It is important for couples to recognize that their relationship will be forever altered due to chronic pain, and life may become burdened with meanings and metaphors of disability and loss, which mar the entire fabric of a couple's existence (Rolland, 1994, p. 330).

Chronic illness literature illustrates the physical and emotional damage incurred by the spouse of a sufferer. Donovan (as cited in Martin, 1989) identified five areas of energy involved in living with chronic pain: (1) preventing and managing medical crisis and regimen, (2) controlling symptoms, (3) socializing, (4) interacting, and (5) normalizing. Normalizing involves covering up, reducing activities, justifying inaction, getting help, and trying to balance options (p. 18).

1.3.4 "We"

Well partners often do not count themselves as living with the illness too. They marginalize or trivialize their own experiences, silencing their side of the story, or simply confirm the dominant story of their ill partner. Much relief exists in encouraging couples to honor themselves and each other by acknowledging the mutuality of their storytelling and experiences (Skerrett, 2003, p. 5). When couples are faced with the tragedy of chronic pain (including despair, uncertainty, isolation, and fear), developing a sense of "we" is critical for promoting coping skills and couple resilience (p. 1). Skerrett's notion of mutuality suggests that what happens to one person happens to both, and that each member of the dyad be aware of the impact of illness on the other, and create a plan to nourish the "we" (p. 6).

The well spouse is advised to discuss limits and needs with the disabled spouse so he or she doesn't become overwhelmed by the illness. We-ness can include separateness, which acknowledges separate needs and realities (Rolland, 1994, pp. 332 -333).

Adding the "we" to the "you-and-I" template creates nurturing, attentiveness, and understanding. In couple's therapy, getting the dyad to move from "you-and-I" to the "we" involves a paradigm shift in thinking on their part (Skerrett, 2003, p. 3). Understanding and learning the language of connection versus disconnection, and empowering the "we" can accomplish "we-ness". For example, a disconnected couple can connect through the feelings they have about their chronic illness experience (Skerrett, 2003, p. 3).

A relationship is developed through dialogue; it is created, transformed, and maintained through the complexities of mutual and multi-vocal storytelling. Partnerships are built upon an interaction between "you," "I," and "we" (Skerrett, 2003, p. 3).

1.3.5 Intimacy

Wynne and Wynne (1986) (as cited in Rolland, 1994) define intimacy as a process whereby couples reveal themselves in both verbal and non-verbal ways, building trust and guarding against betrayal. Intimacy means different things to different people, depending on culture, class, age, and gender. U.S. middle-class intimacy is usually constructed in terms of friendship and shared feelings and interests, whereas working-class intimacy depends more on financial security and mutual protection. All relationships vary in their demands for intellectual, sexual, spiritual, and recreational cohesion (p. 328).

Chronic pain turns an equal relationship into a dominant/dependent one, and it drastically alters shared sexuality (Snelling, 1994, p. 548). Nurturance implies dependency, while intimacy is reciprocal. In Maslow's hierarchy of needs, intimacy is part of the need for affiliation, as well as part of the need for growth (Bral, et al., 2002, p. 2). Many chronic pain couples experience loss of intimacy, which can significantly distress a marriage. Studies suggest 50-75% of suffering couples describe themselves as having little or no sexual contact, and the reasons are profuse. A well spouse may worry about hurting the spouse in pain, be too fatigued, or if fraught with depression, guilt, and anger, she may simply not feel capable of intimacy. A suffering spouse can have erectile

dysfunction due to medication, pain, decreased fitness, and fear of conception (Rolland, 1994; Silver, 2004).

According to Shaughnessy (1986) (as cited in Bral, et al., 2002), intimacy and self-disclosure are critical components of human psychological health. Generally, intimacy involves subtleness in speaking or moving with another person, looking at or away from, and touching during everyday activities (pp. 2-3). Couples who best incorporate and master challenges with the most flexible and broad definitions of roles are those who succeed (Boyd, 2001; Martin, 1989, Rolland, 1994).

Chronic illness is an uninvited third party; it is a demanding trespasser in a relationship. Different illnesses demand different levels of attention at various times. Disc disease is intermittently demanding, while a spinal cord injury can plunge a couple immediately into coping with loss. A couple's survival depends on their ability to cope with the frightening issues of loss and death, and the better they accept and deal with the health issue, the more empowered they will become as a unit. This includes revising their notions of intimacy and reconsidering priorities rather than merely avoiding disability and the constant threat of impending loss (Rolland, 1994, p. 328). Being able to address concerns, disagreements, and other problems is paramount to health (p. 331).

1.3.6 Coping

Coping, according to Lazarus and Folkman (1984) (as cited in Austenfeld & Stanton, 2004), is "...constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 1337). Relationships comprise multiple realities, including

networks of other family and friends, and sustaining a relationship is difficult for many people. Add chronic low back pain, and role predicaments, identity crises, and behavior modification matters become apparent (Lyons & Meade, 1995, pp. 185 -186).

Coping mechanisms are inactive during the anticipatory phase, but are activated when we face a problem; individuals often cope better than anticipated (Kennedy, 2003, p. 46). *Problem-focused coping* involves direct efforts to alter the demands on the person such as problem definition, examining alternative solutions, and creating a plan of action. (Austenfeld & Stanton, 2004, pp. 1337-1338). *Emotion-focused coping* is the attempt to regulate emotions associated with the stressful event, such as avoidance, emotional support seeking, and positive reappraisal (pp. 1337-1338). Our Western culture is steeped in prediction and control over the environment, which logically leads to the conclusion that problem-focused coping is a more useful approach (pp. 1337-1338).

Illness is sometimes the catalyst that brings people closer together. Positive coping and adaptation strategies involve activation of psychosocial and other helpful resources in responding to stress. Relationships are multidirectional and communal, so when couples face significant loss, they must adjust to their new life fairly quickly, or risk destruction (Boyd, 2001, p. 14). Hostile verbal and non-verbal interactions are linked to chronic illness and other disease, and coping is clearly affected by critical remarks. Communal coping is the act of considering a stressor "our" problem instead of "my" or "your" problem (Kowal, et al., 2003, p. 2). Humor is a powerful tool because our bodies release special healing chemicals when we laugh (Silver, 2004, p. 25).

To combat negativity and entropy, health communication research suggests that couples must engage in open and direct dialogue about their lives. This personal disclosure helps identify and stabilize difficult issues and feelings, establish boundaries, and rebalance the relationship (Rolland, 1994, p. 329). Gender roles and expectations are critical in dyads coping with chronic conditions. In a family where the wife/mother is ill, risks of family implosion are largest because women still provide more of the practical and nurturing tasks. Well husbands are more likely to hire a housekeeper, whereas well wives often strive to continue housekeeping duties, endangering their own health. Well men usually have trouble adapting to caregiving roles because nurturing does not coincide with gendered social expectations (Rolland, 1994, pp. 335-336).

Often, one or the other partner fears that communication will hurt the partner or the relationship, and when one person needs to talk about something, the other may not be ready. Rolland (1994) suggests topics to address include: the illness itself, how it might impact the relationship over time, ideas about the cause and what exacerbates it, how to cope with the constant threat of loss, role expectations, personal and relationship priorities, balancing and maintaining relational balance, and legal implications of the terminal phase (p. 329).

The objective of Gullacksen and Lidbeck's (2004) study was to phenomenologically identify and describe major themes involved in chronic pain-induced life changes. This study produced themes in three stages.

Stage I is *prelude* (how long it took to decide pain was chronic), *struggling to restore life* (holding onto familiar lifestyle and identity, but failing to complete expected

roles), *self-deception* (returning too quickly to work, hiding the illness from others, denial), *confirmation* (diagnosis or explanation, doubts of surrounding people), and *acknowledgement* (pain is not temporary, giving up the struggle to restore life, anxiety about new future in pain, trusting own resources) (p. 147).

Stage II is marked by *working through* (pivotal point of realization marked by active adaptation), *sorrow and loss* (mourning previous life), *losing oneself* (doubt of physical capabilities in usual activities), *shedding the 'sick' role* (being cared for by others; long-term becomes troubling, best support is empathic understanding), *defining the problems* (pain moves from body to entire lifestyle), *finding solutions* (repairing existence, learning to live with new conditions demanded by pain), and *picture future effects of coping* (farewell to the past, first step in biographical reinforcement) (p. 148).

Stage III includes *establishing the new course of life* (adjusted self-image used more, coping strategies become normal activities) (p. 149). Maintenance includes *competence of handling future changes* (skillful coping enables quality of life, increased self-knowledge), *a new attitude to life* (accepting a temporary worsening of pain in order to be social), and *regular self-care* (relaxation, exercise) (p. 149).

The effect on a couple is usually in proportion to the degree of pain. Occasional pain allowing normal function some of the time has a lesser effect, whereas a severe back injury resulting in minimal movement and loss of work can have a substantial impact on the couple. While some couples seem to cope and adjust despite severe injury (like Christopher and Dana Reeve), other couples self-destruct from a slighter injury (Silver, 2004, p. 20).

Planning for future role and caregiving changes can help couples cope. For example, at what point should a couple hire an outside caregiver, and what would that mean for the couple? Multigenerational beliefs surface here, as institutionalization can produce shame and guilt in well partners (Rolland, 1994, pp. 332 -333).

Hope can be a coping strategy for endurance (Strandmark, 2004 p. 142), and various strategies emerge, such as adopting an animal companion, supporting others, living in the present moment, and having a more accessible world. Human support can drastically alter negative experiences and encourage feelings of hopefulness (p. 138).

1.3.7 Healthy Couple Relationships

Research has shown that marriage is a buffer against chronic health conditions. Married couples have higher survival rates, higher immune function, and more compliance with medical routines than their non-married counterparts. In distressed couples, however, conflict may hinder these positive aspects (Kowal, et al., 2003, p. 2).

Healthy couple relationships consist of shared goals, positive communication, commitment, humor, and working through crises. These positive aspects increase rewards and pleasures, leading to improved support. When couples communicate directly with sensitivity and openness, they are able to cope and adjust more and achieve a healthy balance of togetherness and separateness (Boyd, 2001, pp. 11-12). We-ness can include separateness that acknowledges separate needs and realities (Rolland, 1994, pp. 332 - 333).

In some studies, pain patients who had solicitous spouses reported higher pain levels and exhibited more pain behavior. Most studies, however, find that having a

supportive spouse helps a chronic pain patient use less medication and experience less pain, which, in turn, improves immune function (Kowal, et al., 2003, p. 2). As cited in Kowal (2003), Hegleson (1993) discovered an inverse relationship between spousal distress and the spousal support provided. Illness affects both patient and spouse adjustment, which influences support provided to patients. Thus, reduced spousal support increases a patient's condition, and undermines social support (p. 3).

The social meanings people attribute to illness impact both the identity and the experience of the sufferer and those in the sufferer's immediate social sphere suffer as well. Relationships help many people buffer against the onslaughts of life; however, chronic low back pain may result in a negative relationship shift (Miller & Timson, 2003, p. 41).

My husband Kevin and I have suffered all the indignities of his chronic low back pain for the past 13 years. He was forced to retire from the Anchorage Police Department after the pain of his injury resulted in too many missed days of work. He had to fight the Retirement Board for the 50% of base pay that was due to him, because he was "too young to be disabled." Along with the pain came a heaping plate of humiliation, contempt, and neglect served up by the Workers' Compensation adjusters and lawyer employed by the Municipality of Anchorage. We are a textbook case of the chronic pain couple as detailed in the above literature review.

Fortunately, or actually unfortunately, I know I am not alone. There are families suffering far worse than we are. I have a job I love where I make a decent living, and our child is healthy. Living this experience and knowing there are millions of other suffering

wives who are not so lucky compelled me to investigate this lifestyle. I wanted to capture their experiences, frustrations, fears, and hopes. I wanted to understand how their lives are similar to and different from mine, and get this understanding out into the world so that other women will know they are not alone.

Chapter 2: Research Methodology

"Marriage is until 'death do us part,' or until 'chronic pain'."

-- Dr. Joe Chandler

The intent of this research is to explore the lived experience of contemporary U.S. American women with male partners experiencing chronic low back pain, and to understand how these women co-construct their realities. I wish to understand how these women feel about themselves, their partners, and their lives together, and how they cope with unique challenges uncommon in the general population. In other words, how are their lived experiences similar to and different from mine?

2.1 Scientific Paradigm

2.1.1 Human Science

"Scientists do their work in and out of a background of theory. This theory comprises a unitary package of beliefs about science and scientific knowledge. It is this set of beliefs that Kuhn calls a paradigm" (Crotty, 1998, p. 35). All research is bound by rules of a certain paradigm, and is created within a certain epistemology. Epistemology then guides the theoretical perspective, which drives the methodology, which in turn, determines the method(s) used for capturing data for analysis. Human Science research immediately conflicts with the dominant quantitative paradigm commonly taught in high school and higher education, and used in research nationwide. However, both social science and human science paradigms are empirical because they are grounded in observed experience, but social science is parametric (uses numbers), while human

science is nominal (uses language). Quantitative research is guided by theory; it is numerical, believed to be objective, controlled, reliable, artificial, explanatory, summative, and defined. Human science research, however, allows theories to emerge from the research; it is natural, synergistic, and not intended to be generalizable. Human science research does not usually use statistical methods, always state a hypothesis, or rely upon deductive methods; rather, it often uses inductive methods whereby the theories emerge from the knowledge and interaction itself. Human action is not rigid, so scientific inquiry should not always be rigid; not everything can be quantified. Janesick (2003) suggests, "Qualitative research design is an act of interpretation from beginning to end" (p. 73). In order to understand and describe the lived experiences of women married to chronic low back pain patients, a qualitative interpretive paradigm is required.

2.2 Epistemology

2.2.1 Constructionism

Within scientific paradigms are epistemologies, or ways of knowing. Crotty (1998) explains that an epistemology "is a way of looking at the world and making sense of it"(p 8). Constructionism is an epistemology that studies the nature of knowledge and justification, and allows multiple theoretical perspectives (Schwandt, 2001, p. 71). Constructionism asserts that knowledge is socially constructed through language and human interaction. Social constructionism, according to Gergen (2004):

> ...renders valid and reliable accounts of individual mental processes...to provide the culture with useful insights into the processes of knowledge acquisition and utilization—to inform the culture of the most effective means by which persons

> can gain cognizance of their surroundings, collect and store information, think through contingencies, recall needed facts, solve problems, make rational plans, and put those plans into action. (p. 5)

Polkinghorne (1988) states that human science should seek not only mathematical certainty (social science), but also results that are also believable and verisimilar (human science) (p. 161). Crotty (1998) emphasizes that Constructionism clearly illustrates that there simply is no true or valid interpretation (p. 47).

Constructionism is the communal generating and transmission of meaning. Meaning is not out there waiting to be discovered; rather, it is socially constructed between people (Crotty, 1998, p. 8) and can be found within everyday language (Polkinghorne, 1988, p. 10). Language carries meaning, constitutes reality, and allows us to gather information about other people's realms of meaning through the messages they give about their experiences (p. 7). Meaning exists as a dynamic collection of associations, amid images and ideas appearing in the forms of perception, remembrance, and imagination (p. 8). Constructionism is reflexive, whereby the entire process is continuously on going, with the researcher as the research tool.

2.3 Theoretical perspective

2.3.1 Social Construction of Reality

A theoretical perspective informs the methodology of a study, and provides a context for the process, grounding the researcher's logic and criteria (Crotty, 1998, p. 3). For this study, I used the social construction of reality as my theoretical perspective, because "All reality, as meaningful reality, is socially constructed. There is no

exception" (p. 54). Social construction of reality, or social constructionism, is the notion that meaning is constructed between people using the world and every object within it:

> ...all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context. (Crotty, 1998, p. 42)

2.4 Methodology

2.4.1 Narrative Inquiry

Methodology analyzes the assumptions, principles, and procedures in a method, which helps the researcher determine how to identify a worthy issue, frame it appropriately, identify what necessitates explanation, and develop logic linking the problem-data generation-analysis-argument (Schwandt, 2001, p. 161). The methodological design of this study is guided by narrative inquiry.

Narrative inquiry is both an empirical approach and an ontological perspective because it captures and describes a person's entire story. Lindlof and Taylor (2002) say "Narrative is absolutely central to art, spirituality, community, and a sense of self, and thus encodes human desire at the deepest levels"(p. 180).

According to narrative theory, a study should focus on lived experience as interpreted by individuals living the experiences. This interpretation involves language and order of meaning, which combine to describe physical experience (Polkinghorne, 1988, p. 125). The goal of narrative inquiry, often unstructured and uncontrolled, is to create a comfortable atmosphere for story telling (Lindlof & Taylor, 2002, p. 181).

2.5 Method

2.5.1 Conversational Interview

A method is "...a procedure, tools, or technique used by the inquirer to generate and analyze data" (Schwandt, 2001, p. 158). An interview, according to Kvale (1996), is a candid discussion between two people where knowledge is created between them. That knowledge production continues as the researcher interprets and reports findings. An interview is not a neutral "thing" to be objectively studied; it is a part of the social world where meaning is constructed (p. 296).

Asking open-ended questions helps create a context where the co-researcher feels comfortable, and has less pressure to provide socially acceptable answers (Polkinghorne, 1988, p. 164). Mishler says we need to include participants as co-researchers, share control with them, and understand their stories with them (p. 164). In Polkinghorne's (1988) study:

> Labov...defines narrative as a 'recapitulation of experience that maintains the strict temporal ordering of events as they occurred in the real world' (p. 164).

He also asserts that each co-researcher's circumstances must be put into context for the reader before correct inferences can be made about their narratives (p. 165). Interviewees, or co-researchers, should be *experienced* and *knowledgeable* about the discussion topic (Rubin & Rubin, 2005, p. 64). Because reality is complex, you must interview a variety of experienced co-researchers to reflect that complexity and make your findings credible (p. 67).

There are many methods of research within the interpretive paradigm. For the purpose of this research, the conversational interview method as described by Kvale works best. The conversational interview method allows the researcher to speak equally with the co-researcher, which in turn allows meaning to emerge within the interaction (Lindlof & Taylor, 2002, pp. 4-5). Josselson and Lieblich (2000) argue, "Seidman (1991) recognizes that, beyond technique, interviewing is also a 'social relationship that must be nurtured, sustained, and then ended gracefully'." (p. 11).

Listening to someone's life details is an intimate experience, and it can be painful to end that thrill of illumination (Rubin & Rubin, 2005, p. 83). Interviews are a continuous process of traveling back and forth between the described world and the current world. The interview then becomes a recording; another reality to be interpreted, transcribed, and put onto paper (Gwyn, 2002, p. 58). Kvale (1996) argues that the interview is as important and valuable to some research approaches as any quantitative method, and that the researcher, in the constructionist epistemology, becomes the research tool (p. 147).

Another goal of qualitative research is transparency. Researchers achieve transparency by carefully accounting for data collection and analysis, and by discussing the entire process. Transparency occurs when a person is able to read a research report and understand the researcher and the process. A researcher should carefully and precisely note what they felt, what they said, and what they observed during the research process. Transparency compels the researcher to stay abreast of the data (Rubin & Rubin, 2005, p. 76-77).

During the interview, the researcher guides the discussion. Interviewing is a craft that relies on the quality of the interviewer as the research instrument. Forms and surveys laden with rules and numbers are replaced with quality interviewing skills that can take years of academic training (Kvale, 1996, pp. 105-106).

> The aim is to arrive at a transparency of the technical equipment, where the proficient craftsman [sic] does not focus on the methods but on the task – in Heidegger's analysis of craftwork it is not the hammer the carpenter focuses on, but the nail and the table. (p. 107)

Interviewing is an art that relies on the sound interpretation of the research instrument, which is the researcher. Mishler notes that interviewers sometimes only use certain pieces of narrative to fit their research, which may impede potential relevant information (Polkinghorne, 1988, p. 162). Yet Labov insists that the point of analysis is to abstract the essence, or plot, of the story from all the co-researchers' stories (p. 164). By asking open-ended questions and allowing prolonged responses, an interviewer creates an atmosphere in which the co-researcher feels less inclined to provide socially acceptable answers, and where the co-researcher feels free to be herself. Interviewers share control with the co-researcher, and together they construct the story (p. 164). Labov suggests that the co-researcher must be provided context so that correct inferences can be made from his or her story (p. 165). According to Kvale (1996), "...the number of interviews tends to be around 15 ± 10. This number may be due to a combination of the time and resources available for the investigation and of the law of diminishing returns" (p. 102).

To understand characteristics of the linguistic constitution of meaning, we must redefine the architectures of knowledge generation. Descriptive research aims to describe events by using existing narrative descriptors people use to order their lives and give meaning to events. Interpretive research aims to understand why something happened by constructing a mutual narrative that connects events to causes (Polkinghorne, 1988, p. 161).

To craft an interview with a co-researcher, seven stages must be met simultaneously in order to create a valid piece of research. A good piece of research must be thematized, designed, interviewed, transcribed, analyzed, validated, and reported. I thematized my design by asking myself what I wanted to understand. The interviews were designed by adapting to the co-researcher's "talk" and education level in their own comfortable territory. I guided the interviews like a ship, kept them on course, asked open-ended, semi-structured questions, used a tape-recorder, and made the interview seem like a normal, every day conversation while guiding it toward my chosen direction. The goal was to create a relaxed atmosphere so co-researchers felt free to share their lived experiences. The audiotape was then transcribed to paper, which helped me reflexively analyze the result of each interview process. Kvale (1996) says "...transcripts are decontextualized conversations; they are abstractions, as topographical maps are abstractions from the original landscape" (p. 165).

I tried with each transcription to validate my findings, asking the co-researcher if my observations matched hers. Validation comes from the co-researcher, the general

public, constant attempts to invalidate my research, and asking if my research reflects the phenomena I'm trying to study. The final report is published here in thesis format.

2.6 Researcher as Research Tool

The author of a qualitative study is at once a performer, an analyst, and a creator (Josselson & Lieblich, 2000, p. 11). The researcher is a research tool, or "Jill-of-all-trades" in the research arena. Denzin and Lincoln (2000) say the researcher, aware of many interpretive paradigms, produces something new with a menagerie of practices that help create understanding in a situation. The researcher must be adaptable, changing methods and techniques to understand a given reality (p. 4). Using multiple methods is known as crystallization; it is an effort to comprehend the topic of interest (p. 8). A researcher of lived experience uses multiple methods of observation and self-reflection to open windows into knowledge. This use of triangulating methods allows the researcher to move among, between, and around various competing paradigms to find a comprehensive view. The researcher is aware of, and sets aside, his or her race, gender, assumptions, class, history, etc., and accounts for them within the research itself. This is reflexivity (Denzin & Lincoln, 2000, p. 4).

In this study, I am both the research tool and the partner of a man living with chronic low back pain. According to Rubin and Rubin (2005), the researcher must examine preconceptions and determine how feelings may tilt the research, then formulate questions to balance accordingly (p. 82). I have certain assumptions from living this lifestyle. Therefore, I am not an objective observer, but a researcher inviting others in similar situations into this arena as co-researchers in an effort to co-construct our stories.

When I met my husband in 1993, he had been injured in the line of duty after responding to a building alarm and jumping a fence to achieve entry. That jump and subsequent fall injured his back. With surgery and an electrical muscle stimulator attached to his back, he was able to return to "the street" for a year and a half. Shortly after we were married, his spinal structure again failed at work while in the line of duty, and he was forced to medically retire.

We spent many years searching for a doctor who could understand the chronic pain experience and finally got lucky. Today Kevin is treated by a highly competent, patient-advocate doctor who also suffers with chronic low back pain. Kevin's chronic pain is managed with narcotics, only because the Municipality's lawyer refuses to allow payment for the artificial disc surgery that would end his pain and get him back to gainful employment. As Kevin lingers on, his vertebrae grow osteocytes, making him increasingly ineligible for surgery. Kevin suffers all the side effects of narcotics, and has tried every conservative treatment and invasive procedure offered to and forced upon him. The Independent Medical Exam (IME) physicians, hired by Workers' Compensation, have unsurprisingly labeled him a malingerer and a drug abuser.

Kevin suffers identity issues because he was a big, strong cop, and now sees himself as "a worthless piece of shit." He helps our young daughter with her homework when he is not knocked out from pain-induced chronic exhaustion. When one IME doctor asked Kevin what he does everyday, Kevin replied, "I'm a stay-at-home-dad." The doctor scoffed, "that's not a *job*." I have been Kevin's health-care champion for many years, supporting him through thick and thin, organizing paperwork, writing letters, making

phone calls, and arming my family with a "we-ness" approach to the onslaught of the medical industry and the Workers' Comp system. I picked up the slack, did the household chores, shopped for groceries, worked full time, ran our daughter to and fro, and attended graduate school to increase my earning potential. I got my hopes up time and again for the artificial disc surgery; I fretted about his near-deadly falls due to medication interactions; I hoped that the Workers' Comp lawyer would see how much cheaper it would be to end Kevin's pain and get him out of the system; we wrote countless letters to authorities hoping that someone in power would care about a guy who faithfully protected our public and who suffers horribly every second of the day. I finally realized that things only work for people who have a lot of money. Personally, I have not had time to create and maintain many friendships, and our family has not been able to co-create memories of recreational outings or vacations. We are both isolated (from each other and society), lonely, and celibate. The agony of his pain, coupled with our imbalanced caregiving/dependent relationship has created significant communication issues that I am not sure can be resolved. My vision of a little house with a yard became the impossible dream as we dove into debt to pay for career retraining and medical costs. Lawyers will only take our case for a retainer fee that we cannot afford.

The social construction of reality accounts for the researcher's place in the research. A researcher comes from a particular social and biographical location, and has a unique perspective on life, which is filtered through his or her perceptive senses. Schwandt (2001) posits, "The constructionist seeks to explain how human beings

interpret or construct some X in specific linguistic, social, and historical contexts" (p. 32).

2.7 Recruitment and Participant Selection

The University of Alaska Institutional Review Board approved this research, and co-researchers were afforded confidentiality. Five participants, each currently in an intimate relationship with a man with chronic low back pain, were chosen as co-researchers for this study. Participants were solicited through word of mouth or via flyer delivered to several medical and two pain clinics in the Fairbanks, Alaska area, and distributed via email to contacts in Anchorage, Alaska; Boise, Idaho; and to the nationwide American Pain Foundation. All co-researchers were many years into their relationships with their partners experiencing chronic low back pain. Because most relationships implode as a result of pain, "because of new HIPAA regulations," (Health Insurance Portability and Accountability Act of 1996) and because of apparent fear on the part of health care professionals, it was difficult to locate participants. One pain clinic in Fairbanks simply refused to speak to me when I handed them my flyer. Fairbanks Memorial Hospital Pain Center, after some deliberation, kindly added their logo to my flyer and posted it in their area. Bassett Army Hospital enthusiastically placed my flyer in their entire area, while a representative of the Veterans Affairs office appeared offended, and asked why I "wished to do research on our American Veterans."

2.8 Procedure

Co-researchers contacted me by phone and/or email, at which point I briefly explained the nature of my study and asked if they would enjoy a conversation about

their lifestyle that could last one to two hours. Because time and personal convenience are absolutely critical for wives of suffering patients, co-researchers chose the meeting location. They were advised that they would be digitally recorded, and that their participation was completely voluntary. They were also aware that their identities would remain strictly confidential, and all read, signed, and received a copy of an Informed Consent Form. I began the interviews with a brief synopsis of my own experience to prime co-researchers with conversational ideas and points. There were no limits on the discussion or topics within. Interviews were then transcribed to my personal computer using pseudonyms as identifiers, and then secured. The UAF Department of Communication will keep all of this research data for five years, after which it will be destroyed.

2.9 Analysis

After each interview, I transcribed the conversation from digital recording to written document for the final analysis process. The goal of narrative inquiry, according to Kvale (1996) is to reveal themes of the subjects' lived experiences of the targeted inquiry (p. 187). Schwandt (2001) says, "If data could speak for themselves, analysis would not be necessary" (p. 6).

I analyzed the data and searched for deeper meaning and common threads between my and my co-researchers' lived experiences. Through narrative methodology and conversational interview method, I searched for meaning inherent within the narratives, and finally, for emerging themes (Kvale, 1996, p. 196). Those themes are the final expectation of narrative human science inquiry.

Chapter 3: The Narrative Interviews

3.1 Tara's Interview

I met Tara, a receptionist at a local doctor's office, while distributing recruitment flyers for my thesis. Tara and I did not know each other before I approached her with my flyer. After I left, Tara took my flyer to the doctor for approval to post it in the waiting area. After she read it and got approval to post it, she emailed me the next day to say she fit the criteria and would be willing to talk to me about her experiences.

We met a couple of days later for the interview in my office conference room on a Saturday during lunch. I brought pizza for us to share. Tara was quiet and reserved, but affable. In her mid-twenties, Tara is pragmatic, straightforward, friendly, and quick to smile. Before the interview began, she read and signed the informed consent form and I made a copy for her. I began the conversation by telling her about my husband's back injury, and our experiences with chronic low back pain. Because she works in a local physician's office, Tara frequently deals with Workers' Compensation claims. We talked about HIPAA laws, and how they have made paperwork transfers quite difficult for insurance companies, doctors, and especially disabled patients.

We then segued into her life experience. She has known Nathan for six years, and they have been married for two. He was injured before they met; a result of passing out and falling over many times due to anemia. Tara explained Nathan's role as a musician in the Army, and how he must march and twist with his instrument, which exacerbates his pain. She struggles for words to clarify her situation; in order to get a promotion or pay

increase, she explains, he must attend a sergeant-training program, where intensive physical training is common. Tara sighs and states incredulously that even though Nathan is a musician, the sergeant-training program requires attendees to carry communication equipment, in addition to a 50-pound rucksack. She says she thinks he pinched a nerve while attending the rigorous training program. His lower back pain is so bad, she reveals, that he cannot run, so he is officially "on profile" and cannot be promoted beyond the rank of E6. Tara further explains that the only option is to wait for the profile to expire in a year, and then complete a running test. Nathan, she exclaims, experiences great stress knowing he cannot get a promotion due to his back pain:

> …once you go beyond E6, then it's….Department of the Army, the music part, and the Department of the Army in general that kind of starts deciding your promotion, and if they see a profile on there, oh you're not physically fit enough, they're probably not gonna take any chances with 'em. So that adds a lot of stress…for him there…and he's in pain a lot…and he's decided not to take flexeril on a lot of nights he'll drink like, one beer to help relax himself…so that way he can go to sleep. And he usually ends up sleeping on the floor a lot of nights because it's much more comfortable for him, and he feels a little better if he sleeps on the floor than he does on the bed. And I've started getting him to go to like, a chiropractor, or something, but the Army won't really do much unless he goes to sick call in the morning and, basically, all they're going to do at sick call is send him home with more flexeril and ibuprophen.

Frustrated, Tara tells me that the Army "has not bothered to take X-rays or MRIs" to look for damage. She compares Nathan's pain disposition to a woman with severe pre-menstrual syndrome; cranky and irritable with mood swings and a "leave me alone" attitude. I can hear the exasperation in her voice. Tara says that there are days when she wonders why she married him, because this isn't what she signed up for.

> Yah, even some of his co-workers…the back pain's gotten bad enough that he's gotten kind of cranky at work…and they kind of notice, and they're like, (whispers) "why did you marry him?" They're like, "I can't believe that you put up with him!"

Tara recently sprained her ankle, so all the housework responsibility that had shifted to her had to be outsourced or not done at all. She explains how his idea of cleaning is to place items in a pile out of the way, then wonder later why he cannot find anything. Tara sighs again, and explains that if Nathan does not or cannot follow the Army doctor's instructions to the letter, or is diagnosed with depression, then he is not eligible for promotion. His pain has totally changed the dynamics of their relationship. Tara notes:

> He doesn't want to do a lot of stuff a lot of times…when we first started dating and seeing each other, we'd go out a lot, and we'd go do things, and spend time with other couples, but now, it's like we do things like maybe once every two or three months, and that's about it.

Tara remarks that she is coping with her lifestyle much better than had she known about it before marriage. Since Nathan became an active Army member (so he could be a

musician and have health benefits), Tara says he went from having occasional pain to constant pain:

> It's really starting to wear down on him, and he's getting…he stresses more, and he's much more…physically tense, and he's trying to hide it, and his body's showing the signs that he's trying to hide pain and frustration. He's starting to go gray, and he's like, obsessing over that now, too.

Tara says that he won't quit unless they forcibly discharge him. He could see a civilian doctor, but he would have to pay 50% of the medical cost after deductible, which they cannot afford. Tri-Care, the medical insurance company the Army uses, is free with drugs, "they hand it out like candy," she says. Tara worries about their future health care options. If Nathan gets out of the military and gets another job, she worries that insurance will say his condition is preexisting. However, if he stays in the military, she is afraid the physical requirements of his work might destroy him. Tara continues to hold out hope that things will improve, or at least, not get worse.

3.2 Ann's Interview

I met Ann by chance when our daughters played on the same soccer team. One sunny afternoon during practice, I overheard her talking with another adult about how her husband Jake was in Germany "getting surgery." I do not easily converse with others, but I knew that all disc surgeries were being done overseas, so I boldly interrupted her conversation and asked if her husband was getting disc surgery. She was surprised at my knowledge of this procedure. We became friends and began socializing because we had so many things in common. She immediately agreed to be a participant in this study, even

though I was in the infancy stages of my research. Much later, I called Ann and told her I was ready to talk. We met at her choice of local restaurants. She is a slender, blonde, blue-eyed schoolteacher who has been married to Jake for 26 years. I explained my research and the informed consent form to her. Then I told her how in my other interviews, I usually begin by explaining my lived experience with a chronic pain husband. Ann and I have had many in-depth, intimate conversations in the past, comparing and contrasting our lives, and we have an established level of trust.

She pays the mortgage, and supports her husband and their two young children on a teacher's salary. She spends her summer "off-time" attending additional professional classes so she will be eligible for raises. Her husband, Jake, was in the Army, and now suffers from debilitating chronic low back pain. When I asked her in a previous conversation what had happened to Jake to cause the pain, she explained that there was no specific, dramatic accident leading to his pain, so they both assume that a chiropractor injured him in the past. It is the only thing they can think of to explain the origin of the pain. Ann has a cheerful, but sorrowful, c'est la vie attitude toward her lifestyle, saying there is nothing she can do to change it. She tells me that Jake is now a stay-at-home dad, is able to stay active working in his garage, and helps the children with their homework after school. She reports:

> A couple of weeks after that (spinal cord stimulator) was done, he was bending over, he was trimming his toenails…he thinks he tweaked something weird…I feel so guilty for not doing his toenails for him.

After 26 years, Jake and Ann now sleep in separate bedrooms. They have not been intimate in over a year, but Ann sleeps better because Jake's snoring does not keep her awake.

Ann has a Master's Degree and continues her education in an effort to "max out" her pay. She is angry that teachers are not paid well, but knows that she is responsible for the career path she chose. She jokes that it is everyone else's fault. She is afraid of not having money to retire on, but takes comfort knowing she can return to live on the family farm in the Midwest. On constantly being asked about her husband's health, she says, "...(sighs) you hate it when people ask about your husband. It just makes you...think about it, and realize that NO, his back's not great, and it's never going to be great."

She laments those personal questions, including questions about why Jake does not sell his guns and tools for money. She must explain that those items have emotional value, use, and meaning for him. He could not recover their personal and actual value by selling them because many are pre-ban; meaning they were previously legal, and now cannot be purchased.

She eagerly tells me how in her house, getting everyone ready to go in the morning is total hell. There is great discord in getting everyone up, dressed, fed, and out the door. Ann and Jake communicate well, she explains, but they argue when it comes to the children and their homework. Ann feels it is Jake's job to stop whatever he is doing at 3:30 p.m., and be available to the children after they get home from school. She was particularly upset when she saw her son's report card and found that he had failed to turn in several units of homework. It is Jake's responsibility, Ann says, to make sure the kids

are completing their work and turning it in. She also laments her perception that Jake treats their daughter better than their son. Ann continues to cope by keeping her spirits up, and says that there are other families relatively worse off than her own.

3.3 Christine's Interview

I have known Christine for several months. She has three grown children, and works full time in an office next to mine. Over the months of getting to know her, I have noticed that her disposition is always vivacious, mischievous, and cheerful. She has a fun and positive outlook on life. I took my flyer to her office to ask her and her co-workers to help me find participants. I was surprised when she identified herself as a candidate, because we had never discussed our intimate relationships. Our conversations were always joking or laughing about things that happened on the job. We set a date and met after work in her office conference room after work. She read and signed the consent form as I began to explain my life scenario in order to get the conversation started.

She is engaged to "Dan," a man experiencing chronic low back pain, and she has been with him for four years. When I asked her what her life is like living with Dan, she replied, "It's Hell. It's like I can never be hurt, ever. I can't have any pain, because he's always worse." Christine explains that when she is stressed, achy, or hurts for any reason, Dan invalidates her pain, saying it's not anywhere near as bad as his. I ask about his job and how he got hurt. She tells me that Dan works on the North Slope as a welder/engineer, and most workers put in 84 hours a week, so they need healthy bodies. Dan fell off a ladder at work several years ago, which hurt him, and the subsequent repetitiveness of his job exacerbated the problem. She reports:

> [Dan] had an accident years ago. He fell off of a ladder and hurt his back really bad and so, just the repetitious working…he's gotta go get these shots, cortisone shots, and his lower disks are compacted, and that was from his accident, and then he has something with underneath his shoulder blade. It's like arthritis, tendonitis, that kind of stuff, and so he's really beat up, and he's very grouchy. He's home, he's not working, so he's freaking out because no money is coming in, and he's hurt, and so it doesn't make me very happy,

Growing up, she explains, Christine's parents always found ways to recreate practically for free, so it is difficult for her when Dan frets about money and wants her to cut back on recreation and stay at home. "I'm not sitting home every weekend just because we can't afford anything anymore…"

Insurance doesn't pay 100% of the medical costs, she says, and his money worries do not make for a happy home. Christine explains how the pain makes Dan angry and difficult to deal with, but he won't take prescribed pain medication, although he does get cortisone shots in his back. Christine helps him whenever she can, with massages, talking, listening, and emotional support. She says he needs to learn compassion for other people's pain, because other people DO experience pain, just not always to the intensity he does. She acknowledges that Dan's always in pain, but says he still works and does things he shouldn't be doing, which then wind up cause more pain:

> …he's trying to restrain me from doing anything, like we're having a snow machine trip planned, and he could work on that painting and doin' this and

> pullin' an engine, or whatever he's doing, which hurts him, but then he tries to take the fun part out because 'I'm injured.' That's not fair.

When I ask where she sees her relationship in the next five years, she smiles and says that they will be just fine if he quits whining. The arguments are all the same, and they have been repeated "a hundred million times, and it's all about Dan, all the time." I point out that men in pain usually focus on their body, on "oh-no's," and that they aren't sure quite how to act when they are in a lot of pain. She responds:

> Me and Dan, we just have it out and then like it's ugly and I am ready to leave the next morning, and it's like I have had it. Dan has been hanging sheetrock on our addition. He writes everything I said on the wall because he's right there working, then [it makes it appear that] I am the one who was the jerk.

She explains that she doesn't write anything on the sheetrock, so it makes her look bad. She jokes, "I just want to frickin' kill him sometimes! There, your back is all better now!" Christine says she loves Dan, and wants to do everything she can to make life and living easier for him.

3.6 Liesl's Interview

Christine told me about how her co-worker, Kyle, who suffers chronic low back pain, and she passed my flyer on to his wife, Liesl. I was not aware that Kyle suffered chronic low back pain, so I was fortunate to make that contact. Kyle consulted his wife Liesl about my research, and she was interested in participating. He gave me his wife's phone number, so I called her, introduced myself, and set up an interview in Christine's office conference room.

Liesl is a petite brunette with a nursing background, studying to become a schoolteacher, and has been married to Kyle for almost 12 years. Liesl read and signed the informed consent form, and I began to explain my own situation to offer some context and begin the conversation. Shortly into the conversation, we discover that we had both spent time in the same small Colorado town in the late 1990's. I explained my husband's injury and the subsequent effect it has had on our communication over the past 12 years. Liesl detailed how Kyle had injured his back after flipping his all-terrain vehicle at the age of 12:

> …he lay down and after that he just…he was…immobile. He couldn't get up, couldn't do anything and uh, you know, they knew it was back pain, but he stayed in bed for about three days…this chiropractor came out and worked on his back …he went from being completely immobile to getting up and be able to walk around…he describes it as kind of as a constant aching feeling that he gets…it has increased over the years as he has gotten older.

She further explains his history, saying that during his military service, the doctors told him to take Motrin and Vioxx. She and Kyle moved to Alaska and bought a house, which required Kyle to cut and stack wood for heat. Both Kyle and Liesl noticed his back pain becoming increasingly worse, but Liesl noted that Kyle is not a complainer. In fact, she said that her nursing background, combined with what she calls Kyle's hard-working, farm-life stoicism, requires her to be hyper-vigilant about his health:

> …he doesn't really complain a lot, but if he does complain that his back is hurting, I *really* believe that he is in a lot of pain.

She told me how she watches his physical activity, and reminds him to take breaks when he's working. Kyle must be careful with small actions, like standing, twisting, or getting out of bed, because one small move, she points out, can have lasting pain consequences. I ask Liesl if Kyle's pain has affected their interpersonal communication at all. She replies:

> I would say no, like I said because he's not much of a complainer. What I do is I try to watch out for him. If he's out there working and I can tell that he's going probably a little overboard I'll go and I'll tell him, and then he, you know, he will stop what he is doing and then just come and take a break because sometimes he just forgets.

She further divulges that Kyle has attended physical therapy classes to learn proper strengthening exercises, and bending/lifting techniques. Soreness, tension, and pain they currently treat with Icy Hot, rest, and massage. Surgery is out of the question, Liesl says, because the success rate of fusion is so low. I introduced Liesl to ProDisc, telling her the success rate is 93%, and few people know about it. Liesl's says her sister suffers horrible debilitating back pain as well:

> …when I was a nurse, both in the hospital and in the clinic setting anyone that would come in for narcotics, you just kind of assume that they're there…looking for a high…that is something that they just teach you automatically like you are kind of ingrained to be on alert, on alert for these…this person, because they are looking for drugs and you know, until like my sister's situation I really didn't have a lot of sympathy for people who had pain issues but now I could really…

I ask Liesl about her hopes and dreams for the future, and what she envisions for her life. She responds that her goal and Kyle's is to eventually work in a third-world country.

> …we were in India this past January and we did a lot of walking, did a lot of climbing, and I was kind of worried about him, you know, how he would do. He did well but I just wonder you know if we ever do decide to do that kind of full-time, would he be able to actually go out there and, and do a lot of physical activity in all those countries where you know the transportation isn't always readily available?

Overall, Liesl and Kyle successfully manage his chronic pain through vigilant oversight. They expect a certain amount of deterioration in his back, and know the pain will always be there, but with constant vigilance, she says they hope it will not progress or get worse as he ages.

3.7 Molly's Interview

Molly found my flyer at a local chiropractic office. A graduate student herself, she knows how hard it is for researchers to find participants, and felt obligated to help me. She emailed me to say she was interested in participating, and I arranged for us to meet at a local Thai restaurant. We arrived and introduced ourselves, and sat down to relax. I give her time to read and sign two copies of the informed consent form; one for each of us.

We both signed informed consent forms, and I offered an information summary, along with a newsletter from the American Pain Community. I explained my husband's

injury and how it has altered our lives and interpersonal communication over time. She explains that she almost didn't show up, "…because I am burned out on the winter; I am having the worst winter ever!"

I smile, and tell her it made me feel great to know I am not alone in my winter blues, and that I am grateful she came. It has taken me considerable time to locate co-researchers who fit the research criteria, so I am thankful Molly is here. Molly is a petite brunette in her late 30's and has been with her husband Brad for 8 years. Molly explains how Brad injured his leg, which caused long-term back pain, and debilitating migraines. Later, unrelated gall bladder issues and instances of kidney failure compounded the entire health experience. Brad's previous career in the food industry, she explained, was impossible to maintain with severe physical limitations, and the unforgiving machismo atmosphere that exists in the kitchen workplace made things worse. She went on to describe how Brad's body was thrown out of alignment after wearing a leg air-brace and then an external form-fitting brace for four years. This contributed to his perpetual back, shoulder, and neck pain. He cannot move or function at particular times, and he has moved into perpetual back pain cycles. In 2005, he began suffering migraines.

Molly actively described how, together, she and Brad did everything the professionals advised to manage his pain; taking prescription pills, changing diet, and changing activities. At this point, she gets misty eyed:

> His chiropractor…sorry (for tearing up) ….his chiropractor is even boggled by the whole thing because…he has a pretty good medical background and he's interested in medical both Western medicine and [Eastern], so he is able to

> explain to Brian where it's at...and the fact that he cannot identify anything...umm...within his spine...the chiropractor can't find anything that is causing nerve damage, you know, that would make [pain] happen

Molly says she finds it disturbing that after MRIs, x-rays, and all other tests, no doctor can find anything wrong with Brad. When I asked if there has ever been professional insinuation that Brad's problems are all in his head, I received a frustrated and emphatic "OH YES!" She began struggling emotionally at this point to fight back tears:

> ...he kind of has all different layers of health issues. He had gall bladder disease. Immediately after he got the migraines he started umm...having undiagnosed kidney (struggles) failure every three months (fights tears). It was so ridiculous! Sorry (tearing up)...so basically, he had gall bladder disease and it didn't show as gall stones because there were no gall stones and he would have kidney failure every once in a while which basically means you don't urinate and you have to go to the hospital and they would umm...test him, and all of his tests would come back the same, 'your liver function is out of control, your kidney function is inappropriate.' At that time, he had just started having the migraines so the doctor was towards the end very cynical about...you know...what was going on, and I actually think that particular -- it took a year and a half and five visits to the ER, three times being admitted for them to finally acknowledge that it was probably his gall bladder and they took it out. I think that's probably because we were in Fairbanks...we didn't have the range of medical diagnosis.

To make matters worse, the doctor gave Molly a pamphlet on chronic vomiting syndrome and told her, "you know, this is the best that I can do." She says she feels beaten down by the medical establishment. She has no doubt her husband is in pain and is suffering. At one point, she says, he was jaundiced, and the health care providers still doubted that there was a problem.

Brad was eventually referred to an Anchorage nephrologist (kidney specialist), whom she claims insisted he knew exactly what the problem was, and that Brad needed to come in immediately. Because they were unable to afford the trip to Anchorage right away, the doctor sent Brad in for tests in Fairbanks, but never followed up with results:

> …so we went and took the test, and we never heard, never heard, and finally he had his next incident and I called him and they're like, "his tests were fine and he's the picture of perfect health." And I just (incredulously)…oh that was like, the *bottom*. I wrote this nasty letter to him, I carbon copied it to the internist who referred me to him, and you know if you don't know what's going on I'd completely understand, but (chuckles incredulously) there's definitely something wrong. It may not be within your specialty but there's definitely something wrong and to say that someone's the picture of perfect health on paper....

Since having his gall bladder removed, Brad's health has improved, but he still has down days. Brad can still function (attend classes and do homework) during what Molly calls his "mild down times," but is not functional during "stronger down times." Molly scoffs at the University's health care program:

> The student insurance is horrible, they pay $1000 per incident but they'll diagnose everything as a different incident so it's like a $400 incident. And then the co-pay…"

Fortunately, they got other insurance just before Brad had his kidney disease diagnosis. He was diagnosed with kidney disease then doctors later realized it was *just* gall bladder disease.

She feels they've formed a "we" relationship to cope with the medical establishment. Chuckling, she explains that she tries not to talk about any of it to outsiders, because the more she does, the crazier it all sounds. Molly's eyes well up again, and I offer to stop the interview. I tell her I know how frustrating it all is, and we discuss the machismo nature of both our husband's previous jobs. She goes on to explain how Brad now has a desk job, is pleased to find the work enjoyable, and his co-workers supportive and understanding; "it's a lot more nurturing environment," she says.

> I ask how Brad's pain has changed their relational communication. She continued:
>
> You know being in a caretaker role … it causes conflicts because when he's down, I'm taking care of things, and taking care of him…and that's uncomfortable for him…

She says she is learning to recognize the pain cycles, and can better help Brad, but alternately, she also becomes more "normal," or "less nurturing," which is also uncomfortable for him. We talk about how our immunity to the sounds of pain and the difficulties make us both look heartless from an outside perspective.

Molly and Brad do not plan to have children. We discuss the unpredictable nature of chronic pain, and how it frequently ruins the best laid plans. The long, dark, cold winters contribute to seasonal affective disorder, which compounds the chronic pain experience for both of us in a negative way. We admit to each other that at times, we find ourselves emotionally overwhelmed.

Because sleep is elusive for my husband in many ways, I asked Molly specifically about beds. She explained how, on a visit to Tokyo, they found a futon surprisingly uncomfortable, but have since found great relief with a plain air mattress, like the kind you take out for guests. Molly talked about her difficulty coping with how exhausted her husband seems to be. At first, she says, she attributed it to his swing shift lifestyle, but now there doesn't seem to be a reason to take a nap after getting up and taking a shower. I responded with information about how my husband sleeps for about 15 hours a day. I explained that Kevin's natural pain-killing endorphins are all gone, and the pain takes all his energy. He needs every bit of leftover energy to take a shower, and then must nap to recuperate. Molly expressed surprise and simultaneous relief to have that understanding.

We moved into discussion about narcotics and painkillers. She admitted it took her a while to get comfortable with Brad's painkiller use, because she didn't want him to rely on them in case the doctor stopped prescribing. I mentioned the difference between addiction and physical dependence, then we discussed drug side effects, and how Brad must take an anti-spasmodic to counteract his stomach locking up from all the pills he consumes.

I asked Molly about her hopes and dreams, and her vision of the future. She has no extravagant expectations, but settling into good careers they're happy with means a lot to her. She said that Brad is less optimistic, which causes conflict between them. Going home to the south lifts both their spirits; she says being around family and getting sunshine works wonders for them. She says that starting from scratch in a new medical community is not something she is looking forward to:

> ...we have to go through both therapists and people to find out who would want to handle being with him and that he likes...it's not an easy prospect because he has to find someone *he* likes and that's particular also.

I mention that the American Pain Network and other web sites rate and refer doctors to save time, money, and exasperation of going from doctor to doctor to find a competent one. Molly noted that once Brad had the medical label of "migraine sufferer" people became more willing to accept his pain-induced lethargy and exhaustion, no matter what the actual, organic cause. She conveys frustration that Brad is searching for one label to identify his problem, whereas she is more pragmatic, and realizes it's a conglomeration of pain issues that all interconnect. Overall, Molly says she is distressed with the position she finds herself in at present, but she is hopeful that moving south, being closer to family, and finding good jobs will help make life easier for them both.

Chapter 4: Research Findings

I began this research due to my own experiences with spousal chronic low back pain. The man I married was an intelligent, accomplished, compassionate man, who, due to chronic pain and medication side effects, slowly became the irritable, ill, exhausted, and isolated individual I now live with. Maintaining a long-term marriage or partnership is difficult in itself; add chronic pain, exhaustion, diminished capacities, workers' compensation lawyers, doctors, and medication, and life becomes an unbelievable, living nightmare with no end in sight. To better understand my own lived experience, I sought out women who were in a similar social situation.

The conversational interviews presented for this work are co-constructions of reality created between my co-researchers and me. In evaluating my interpretations as a researcher, I understand and account for my own biases in the research. Because I was both the research tool and the partner of a man living with chronic low back pain, I was careful to recognize that my perceptions may affect my research. (Rubin & Rubin, 2005, p. 82). I must also reflexively analyze and re-present the lived experiences of my co-researchers (Denzin & Lincoln, 2000, p. 4).

Conversational research interviewing results in a description and an interpretation of the themes in the co-researchers' lived experience (Kvale, 1996, p. 187). Each of these women provides a unique, candid perspective on living with a man experiencing chronic low back pain. Using narrative methodology, I carefully considered and immersed myself in both the audio taped and the transcribed data. As I worked, I also included my knowledge from my review of the literature to fully characterize each

perspective. The analysis of the data suggests the theme of frustration was most prevalent, with five overlapping and emergent sub-themes: (1) finances, (2) caregiving, (3) relational communication, (4) medication, and (5) emotional taxation.

4.1 Theme: Frustration

Each co-researcher and I were acutely aware of the impact that our husbands' chronic low back pain has had on our lives. The main theme that threads through all interviews is *frustration*, defined by Webster's dictionary as "disappointment; to cause to have no effect; to prevent from achieving an objective" (Agnes & Gralnik, 2001, p. 571). Whether it is fear, stress, financial ruin, the medical industry, or troublesome communication, the co-researchers all felt frustrated to various extents.

4.1.1 Sub-theme 1: Finances

All co-researchers are gainfully employed. Tara, Molly, and Liesl's husbands are also gainfully employed, albeit with varying levels of physical difficulty. Ann's husband and mine stay home, and Christine's husband finds work when he can. Tara, Ann, Christine, and Molly all expressed frustration about finances. Tara is frustrated that the nature of Nathan's profession as a musician requires him to bend and twist, thus exacerbating his pain. Being in the Army, he is required to attend an intensive physical training program to qualify for a pay increase or promotion. That requirement will almost inevitably lead to permanent professional stagnation. She is concerned about their future health care options, considering the insurance industry's notion of "pre-existing conditions." They both experience great stress knowing he cannot get a promotion in the Army due to his back pain. He tries hard to hide his injury by appearing as able-bodied as

possible, and going through the physical motions expected of him. Matthews & Harrington (2000) posit:

> ...image management and strategic self-disclosure become critical skills to have for identity maintenance. This is especially important for the invisibly disabled, as they 'look' healthy, so therefore should 'act' healthy according to observers. (p. 410)

Ann's teaching salary supports her family of four, but there is not extra money left over at the end of the month. She works during the summer to "max out" her salary. Ann says she is afraid of having no money to retire on. She pays the mortgage, and supports Jake and their two young children on her teacher's salary. They went so far as to refinance their home to pay for an overseas spinal surgery, but then could not afford the additional follow-up care. Consequently, that surgery did not work as expected. After spending thousands of dollars and trying many remedies, Ann is dejected that Jake still has pain.

Christine finds Dan's obsession with their lack of funds extremely frustrating. He wants her to stay home every weekend so she will not unnecessarily spend money on recreational activities. Dan's insurance does not pay 100%, so they are left with hefty medical bills on top of reduced finances, and his money fears create an unhappy home, full of stress. He wants her to cut back on recreation, but she refuses to stay home every weekend for lack of money.

Molly and Brad are working, but pay graduate student tuition, and cannot afford a new bed, or trips to see better doctors in Anchorage. Molly scoffs at the University's

health care program: "The student insurance is horrible, they pay $1000 per incident but they'll diagnose everything as a different incident so it's like a $400 incident. And then the co-pay..." It is in an insurance company's best interest to recognize as few medical labels as possible while still advertising their value to consumers. Likewise, it is in social programs' best interest to recognize as few medical labels and conditions as possible without drawing the attention of political opposition (Wendell, 1996, p. 132).

The literature echoes the financial frustrations the co-researchers divulge. Wendell (1996) notes that trying every suggested remedy is a full time job that will exhaust personal finances (p. 98). Chronic illness drastically reduces financial, physical, work, and social resources, leading to a general detrimental effect on family wellness (Silver, 2004; Lyons, 1995).

4.1.2 Sub-theme 2: Caregiving

Caregiving often displaces intimacy in chronic pain relationships. There is a difference between intimacy and nurturance, the former being egalitarian, the latter being dependence (Bral, et al., 2002 pp. 1-2). Sexual intimacy is drastically reduced, as is social exchange and support. There is a need for sufferers to be reciprocal and equal (Lyons & Meade, 1995, p. 187).

Intimacy is severely diminished in four of the co-researchers' relationships, and in my own. For my relationship, it began with back pain causing grumpiness, leading to caregiving, which deteriorated into communication issues and lack of intimacy. Two co-researchers did not discuss their intimacy issues. Patient-caregiver roles compete with the

expected equal-partner roles marriage affords. A disabled husband will no longer be able to perform physical tasks or provide the same income (Rolland, 1994, p. 332).

Tara had to take on the majority of housework after Nathan got injured. She was already doing much of it anyway, but when she sprained her ankle, all the housework responsibility that had shifted to her had to be outsourced or not done at all. Nathan is too tired from the pain to help. Well spouses must understand that the pained spouse is feeling insecure, stressed, and frustrated. Encouraging the pained spouse to do as much as they can helps improve self-esteem, as opposed to doing everything for them (Silver, 2004, p. 33).

Christine tries to help Dan, by listening empathically, giving him massages, and keeping humor flowing in the household. Researchers have discovered that partners who provide support actually facilitate coping, rather than reinforcing pain behavior (Gullacksen & Lidbeck, 2004, p. 152.)

Liesl feels that her hyper-vigilance keeps her husband from further injuring his back, and Molly is very involved in Brad's medical element. Both of them are their husbands' biggest supporter and they help manage health care and records.

As my husband's health has continued to decline, I have become increasingly involved in his health care management. Neglecting my own relational needs, I organized mountains of medical and legal paperwork and picked up the slack while he struggled to get the smallest measure of restful sleep. Partners and spouses often bear the burden of caring for CLBP sufferers. Their needs also come into play, as their mental and psychological health are also at risk (Miller, & Timson, 2003, p. 35).

Sometimes a well spouse struggles with whether to continue in a revised version of the original relationship, or to define it strictly in caregiving terms (Rolland, 1994, p. 335). A caregiving relationship can turn into one mirroring a parent-child relationship, where adult intimacy is gone (p. 335).

4.1.3 Sub-theme 3: Relational Communication

My own relationship began as an intellectual partnership, but degraded into an exercise in hyper vigilance and caregiving. My relational communication with my husband has suffered the most, as his quick wit and mental agility have decayed into slowed response, confused meaning, and conflict.

Tara says Nathan is cranky, irritable, and moody, even around his co-workers, and she believes this is a direct result of his chronic pain and lack of relief. As the research demonstrates, a chronic illness impacts and challenges couples' communication skills (Rolland, 1994, p. 329).

Ann and Jake argue when it comes to the children and their homework, and every morning in the process of getting everyone out the door. Because pain cannot be seen, those trying to communicate it struggle (Jackson, 2000, p. 157). Chronic pain sufferers must understand how their condition and reactions affect the people around them, and friends and family must learn how to respond to the changes (Silver, 2004, p. 3).

Christine and Dan fight frequently, and she gets intensely frustrated with the arguing. She says that she just wants to (figuratively) kill him. She explains how the pain makes Dan angry and difficult to deal with, so much so that he invalidates any pain she experiences. They have frequent, heated arguments, causing her to want to leave the

relationship. Conversely, Christine helps Dan in various ways with massages, talking, listening, and emotional support. Often couples experiencing illness will have two different realities, and feel they each must win the other over to their side (Skerrett, 2003, p. 6). Wendell points out that there are few words in our language to describe pain, so patients struggle to explain pain and suffering (Wendell, 1996, p. 134).

Liesl's communication with her husband has perhaps improved, or at least not gotten worse, due to his back pain, and she says she does not believe that Kyle's back pain has affected their communication as husband and wife. Kyle accepts her authority and knowledge about health care, and responds to her directives. They work synergistically to prevent his pain from becoming a significant problem in their relationship. For instance, Liesl eventually became the one who bent over, picked up, and stacked the wood to lighten Kyle's load and to preemptively avoid possible exacerbations of his condition.

Molly admits to bitter arguments with Brad over many subjects, including his chronic exhaustion. She says her caregiving role is required, but causes conflicts because Brad is uncomfortable with that type of relationship. Molly is upset and confused by Brad's need to nap shortly after rising in the morning, and does not understand why he is always so exhausted. My husband Kevin sleeps an average of 15 hours a day. Toileting alone takes almost all of his energy. Exhaustion leads to fewer opportunities for daily relational maintenance communication, and certainly to reduced intimacy. Molly has a hard time coping with how exhausted her husband seems to be. At first she attributed it to his swing-shift lifestyle, but now there does not seem to her to be a reason for taking a

nap right after getting up and taking a shower. In fact, pain consumes the brain's endorphins, and thus, like other co-researchers' husbands, takes all his energy. Brad needs all his energy to take a shower, then must nap to recoup. Those in pain exert much energy paying attention to their situation. (Wendell, 1996, p. 173). With chronic pain patients, energy is money, and the sufferer has to consider how to spend that capital (Silver, 2004, p. 93).

4.1.4 Sub-theme 4: Medication

All co-researchers were actively involved in their husbands' medical treatment. Tara is frustrated with the Army's entire medical program. Nathan must report to "sick call" and wait several hours to get medical attention, much like a civilian emergency room. He is rewarded with either ineffective ibuprophen or sleep-inducing flexeril. Tri-Care, the Army's medical insurance provider, hands drugs out "like candy," Tara says. But medical treatments often only affect one dimension of pain (White, 2002, p. 21). The doctors have not taken X-rays or MRIs of Nathan's back to identify or diagnose a possible physical injury. He keeps going back, and they keep giving him the same ineffective remedy, per protocol. If Nathan does not follow the Army's medical protocol to the letter, he is automatically ineligible for a promotion. Silver (2004) notes:

> The person in pain spends a significant amount of time and energy seeking medical attention. Side effects of medicine alone cause a myriad of other problems, to include lowered energy. (p. 24)

Ann's husband Jake was prescribed painkillers by a local physician, but when that did not completely alleviate his pain, the doctor decided that Jake was addicted to pain

medication. The doctor sent him to a local pain clinic known for taking patients off all medication. The pain clinic labeled him an addict, sent him to a rehabilitation clinic out of state, and blacklisted him with local pharmacies. The pain remained. Jake and Ann refinanced their home to send Jake to Germany for an artificial disc implant, which has been done in Europe for almost 30 years. That disc slipped, and it was too expensive to send him overseas for follow-up care. Jake was subsequently fit with an internal spinal cord stimulator. Although he continues to experience pain, he cannot take medication, and Ann's resulting frustration is palpable.

Christine says Dan was prescribed painkillers, but he refuses to take any prescription medication. That may be the wisest choice, depending upon the level of excruciation one can tolerate. My husband experiences many side effects from pain medication, including alternating constipation/diarrhea, splitting headaches, devastating lethargy, aural hallucinations, obesity, high blood pressure, low blood oxygen. The list goes on and on.

Liesl helps Kyle with regular over-the-counter remedies, since their synergistic vigilance and lesser injury level keeps them from needing heavy medical industry assistance. Kowal, et al., (2003) asserts, "Having a supportive spouse helps a chronic pain patient use less medication and experience less pain, and it leads to improved immune function" (p. 2).

Molly felt great stress because she feared the doctor would stop prescribing medication after Brad had come to rely on them for pain control. Brad must also take an anti-spasmodic medication because his stomach "locks up" from all of the other pills he

must consume. When I asked Molly if there has ever been professional insinuation that Brad's problems are all in his head, I received a frustrated and emphatic "yes." Kennedy (2003) asserts that most people and physicians are unwilling to give up the institutionalized biomedical paradigm. People have pain, so they believe they need to see doctor after doctor until one does the proper archaeology to discover the actual problem. Then people become desperate, and they find resistance in the medical community with the prototypical attitude that "it's in your head." That thought produces much of the chasm between mental illness and physical illness (p. 24).

Thanks to Descartes, Western culture sees the body as a machine; a whole sum of parts. Thus, diagnosis and treatment intend to locate a lesion or some measurable, quantifiable course of remediation. The person experiencing the pain or problem becomes persona-non-grata, while the physician's perspective remains socially valued. This asymmetry of power isolates pain sufferers from their bodies, and makes them willing to ignore problems their physicians decide are unworthy (Wendell, 1996, p. 120). During one of Brad's emergency events, Molly called the nephrologist to get the diagnostic test results. The nephrologist wrote in his report that Brad is "the picture of perfect health." That unfeeling, unrealistic, and unsympathetic conclusion caused Molly to "hit bottom." She felt something was horribly wrong with her husband, and the doctor was simply ignoring it. When a person is in pain or is very ill, and a physician declares that there is nothing wrong, the patient must choose between their own feelings and the opinion of a professional whom they have likely trusted for years (Wendell, 1996, p. 124).

We must somehow remain connected to a world that denies our own experiences of our bodies; one that encourages us to ignore what we feel, until we find the right doctor. Those who are lucky enough to get a propitious label, get epistemic validation (Wendell, 1996, p. 125).

4.1.5 Sub-theme 5: Emotional Taxation

These women are all impacted by their partner's chronic low back pain, which is the main source of frustration in their lives. Tara says this is not what she had in mind when she married. She thinks she is coping all right, but life could be a lot better, and she feels especially isolated now. They used to socialize frequently, but now only go out once every two months or so. Emotions are normal responses in every relationship, yet they are even more significant in chronic illness relationships. These couples experience anger, guilt, shame, and other powerful emotions as they grieve the loss of their "normal" life, along with the potential of imminent death (Kowal, et al., 2003, p. 6).

Ann speaks of weariness at answering friends' and family's questions about Jake's health because there is never any improvement. Although she sleeps better without his snoring, she is bothered that they sleep in separate bedrooms because they have lost their intimate connection.

Christine is on the verge of leaving Dan regularly. Dan's grumpiness and anger are almost too much for her to handle. Liesl worries about the goal she shares with Kyle of traveling in India, and his ability to participate when they're both older. Molly is often emotionally overwhelmed and looks forward to being around family when they move south. An environment of family support, along with regular sunshine and a warmer

climate will do wonders for her, she feels. Family members can relate better to emotional expression, both their own and others' (Austenfeld & Stanton, 2004, p. 1342).

My husband, homebound and unable to keep appointments because his body does not cooperate, stopped socializing so as not to continually let people down. A significant problem for pain-disabled people is boredom, which is defined as cognitive and sensory deprivation, combined with social isolation and restricted mobility. Chronic pain disrupts social involvement, recreation, and other relationships, especially when they interfere with communication and mobility (McDaniel, 1976, p. 61)

The frustration and exhaustion extends to friends when they cannot rely on Kevin to keep a date. Physicians' offices get irritated and treat him poorly when he repeatedly cancels appointments because he simply cannot get out of bed. Tara and Nathan used to socialize frequently, but now only get out about once every two or three months. Many pain patients in Jackson's (2000) study found socializing so frustrating that they gave it up completely (p. 46).

Studies have shown that chronic pain patients have difficulty with running, dancing, walking, sitting, using stairs, sleeping, and having sex. Having no energy, no ability to concentrate, depression, and with suicidal thoughts, all exacerbate sufferers' lives and relationships. Depression is quite common for chronic pain patients (White, 2002; Jackson, 2000).

The theme of frustration with its corresponding sub-themes of finances, caregiving, relational communication, medication, and emotional taxation all emerge from my attentive immersion in the literature, my saturation in the interview capta, and

my own reflexive introspection. The co-researchers' descriptions of their lived experiences reflect my own. The overall theme of "frustration" encompasses the general state of mind each of us experiences every single day. The sub theme of "finances" reveals the stressful concern we all live with in experiencing decreased income combined with increased medical costs. "Caregiving" speaks to the unwanted role we, as wives, find ourselves in that competes aggressively with an equal partnership and intimacy. "Relational communication" demonstrates how pain can cause interpersonal relating and intimacy to become strained and unpleasant, while "medication" reveals the fright and concern in coping with medication, doctors' orders, stigma, and side effects. "Emotional taxation" reveals the range of emotions wives of pain sufferers go through and live with every day.

This study shows that the lived experience of chronic pain has significant overall impact on the wives of sufferers, and that further research into relationships involving chronic pain is desirable. Julie Silver (2004) embedded herself in a chronic pain clinic in her magnificent research, *Chronic Pain and the Family.* Even richer sources for research are the poor, uninsured, misdiagnosed, and undiagnosed chronic pain sufferers and their families who are more difficult to locate. Including both partners as research participants, or perhaps other family members, could provide even more powerful insight into this poorly explored topic.

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Appendices
Appendix A: Informed Consent

Study Title:

A narrative study of the lived experience of contemporary American women in intimate relationships with men who have Chronic Low Back Pain.

IRB# 06-69 Date Approved 09-22-06

Description of the Study:
You are being asked to take part in this research study. You fit the research criteria. You have agreed to an interview date and time. This study is about your experience in an intimate relationship with your Chronic Low Back Pain partner. Please read this form and ask any questions you like before you agree to participate. If you agree, I will interview you for 1 to 2 hours. We will talk about your life with a man who has chronic low back pain.

Confidentiality:
Our discussion will be audiotaped. I will later type the recording on the computer, and study it with others. Your name will not be used. You will not be directly connected to any part of this study. Your responses in this study will be confidential. After five years, all writings and recordings will be destroyed. This study is about the lived experience of American women in an intimate relationship with men who have chronic low back pain. This research may be used in papers, presentations, and publications. You will never be personally identified.

Risks and Benefits of Being in the Study:
I expect no risks or discomforts for you. The focus is on your personal life experiences. If you feel distressed at any point, we will immediately change the subject. This study might benefit you and society. I hope to learn more about what life is like for other women in your situation. You may gain more understanding of your own experiences. You may gain more understanding about your life situation. There is no guarantee that you will benefit from taking part in this study.

Voluntary Nature of the Study:
Your decision to take part in the study is voluntary. You are free to stop participating at any time without penalty. If you choose not to continue, any information you have provided will not be used. All of your information will be strictly confidential. I will use a pseudonym instead of your name.

Contacts and Questions:
If you have questions now, please ask. If you have questions later, you may contact me, Gina Heath, at 474-5103, or by email at fngh1@uaf.net. You may contact my thesis advisor, Dr. Jin Brown at 474-7405 or ffjgb@uaf.edu.

If you have questions or concerns about your rights as a research subject, please contact the Research Coordinator in the Office of Research Integrity at 474-7800 (Fairbanks area) or 1-866-876-7800 (outside the Fairbanks area) or fyirb@uaf.edu.

Statement of Consent:
I understand what was described above. My questions have been answered to my satisfaction. I agree to participate in this study. I have been provided a copy of this form.

Signature of Research Participant	Date
Name (Printed)	
Signature of Person Obtaining Consent	Date
Name (Printed)	

Appendix B: Recruitment Flyer

UAF Department of Communication
PO Box 755680
Fairbanks, AK
99775
907-474-7405

Are you a *woman* in an intimate relationship with a man who has Chronic Low Back Pain ? CLBP

(chronic means lasting more than 6 consecutive months)

Gina Heath
PO Box 84172
Fairbanks, AK 99708
alderavenue@hotmail.cor
907-455-8107 (w)

Seeking women ages 18 to 100 (who are currently in an intimate relationship with a man with CLBP) for a one or two hour (private and anonymous) face-to-face interview. You will not be identified in any way.

The purpose of this research is to explore the lived experience of American women with male partners experiencing chronic low back pain (CLBP). CLBP sufferers fall into a unique, invisible realm that only they can comprehend. Partners of CLBP sufferers (like me) partly belong to this stigmatized world, have insight into it, and often respond to it either in tandem with the medical establishment, or not. Often undertreated, chronic pain impacts every aspect of a sufferer's life, and the spouse must mitigate and help negotiate life for the couple.

An interview will be scheduled at your convenience. Before the interview, I will explain the purpose of the study, and ask for your informed consent to voluntarily participate. You may withdraw at any time for any reason. You may choose to discuss, or not, any topic emerging during the interview. I will use narrative interview techniques to construct an understanding of your lived experience in formulating and defining your lived experience. There is no monetary compensation for participation, but you may gain new insights into, and a better understanding of, your own lived experience. Your participation may be both therapeutic and cathartic on many levels. I will provide support group information for your benefit, and you may find relief in knowing you are not alone.

Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6172	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712	Chronic Low Back Pain Study alderavenue@hotmail.com 907-322-6712

Appendix C: Information Summary for Co-researchers

A narrative study of the lived experience of contemporary American women in intimate relationships with men who have Chronic Low Back Pain.

By Gina Heath, graduate student, University of Alaska Fairbanks, Department of Professional Communication. I am studying the lived experience of contemporary American women in an intimate relationship with men who have chronic low back pain. You are being asked to participate in this study because you fit the research criteria, and you have volunteered. You are being asked to talk about what your life is like living with a man who has chronic low back pain.

If you choose to continue now, you will participate in an interview lasting about one or two hours. Your interview will be audio-taped and kept in my personal computer so I can create transcripts and study it with others. My thesis advisor is Dr. Jin Brown. He and I will be the only people with access to the material. A record of your participation will be kept, but your name and information will be held in strict confidentiality in a locked file drawer at the UAF Department of Communication. I will use a pseudonym instead of your name.

If you have any questions about this study, please contact me.

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American Chronic Pain Association
http://www.theacpa.org/

Chronic Pain Support Group
http://www.chronicpainsupport.org/

National Institutes of Health
National Institute of Neurological Disorders and Stroke
Low Back Pain Fact Sheet
http://www.ninds.nih.gov/disorders/backpain/detail_backpain.htm